ARIZONA LONG TERM CARE SYSTEM (ALTCS)
CONSUMERS SPEAK OUT

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I. PROJECT DESIGN

A. Background

AHCCCS' LTC Program – Arizona Long Term Care System (ALTCS)

Arizona's Health Care Cost Containment System (AHCCCS) was established in 1982 as a comprehensive Title XIX managed care program authorized under a Section 1115 demonstration waiver. In 1987, Arizona passed legislation to include a long term care component known as the Arizona Long Term Care System (ALTCS). There are two populations serviced in this program, Elderly and Physically Disabled (EPD) and Developmentally Disabled (DD). The EPD population can be defined as those individuals who are elderly (over 65 years of age) or those who have a physical disability regardless of age and have been determined to be "at risk" of institutionalization. The DD population includes those individuals with a developmental disability regardless of age that are determined to be "at risk" of institutionalization in an intermediate care facility for the mentally retarded. In addition, those individuals with a psychiatric condition may be included if there is a non-psychiatric condition or developmental disability that by itself or in combination with other medical conditions (including psychiatric) places them "at risk" of institutionalization. The primary reason individuals need long term care is for assistance with activities of daily living, such as eating, bathing, and dressing. The scope of this research project pertains exclusively to the EPD population aged 18 and over.

Growth and Challenges

The EPD long term care population has evolved into a highly diverse group of individuals. Some of the factors that have contributed to the diversity of this population include: the rapid growth in the number of persons over the age of 85, the significant increase in the last few years in the number of persons 18 to 64 years of age, and the fact that almost half of the ALTCS population currently lives in the community rather than in nursing homes. At the start of this study, enrollment for the ALTCS EPD population in Arizona was approximately 17,500, with approximately 54 percent (9,400) residing in Maricopa County.

ALTCS Managed Care Environment

Arizona is the first state to competitively bid the Medicaid managed care long term care program on a statewide basis. Arizona's program is unique because the program includes not only a medical services component, but also offers an array of fully integrated long term care services (e.g., home and community-based services, case management, behavioral health and nursing facilities). Care is coordinated and managed by seven EPD health plans in the state. Currently, at least one managed care organization (commonly referred to in the ALTCS system as a health plan) operates in each county. With the rewriting of A.R.S. § 36-2940, AHCCCS competitively awarded three EPD contracts to provide long term care services for the ALTCS EPD program in Maricopa County. Every new applicant and all existing consumers in Maricopa County now have a choice of health plans: Lifemark Health Plans, Maricopa Long Term Care Plan, or Mercy Care Plan.

Consumer Satisfaction

The purpose of this research is to assist AHCCCS in assessing consumer satisfaction with long term care services in Maricopa County before and after the competitive bid. This report covers the post-survey of 2001 by examining the number of existing members who remained with current contractors and those who switched to another health plan. An analysis was then conducted comparing those who changed health plans versus those who did not change health plans on long term care services.

B. Project Goal

Health Services Advisory Group, Inc. (HSAG) and AHCCCS used the data collected in Phase III to address the following project goal:

> Determine if consumer satisfaction with long term care services is affected by choice.

C. Project Phases

It was determined that three project phases were necessary in order to achieve the goals and complete the necessary tasks associated with the project. Phase I began in May of 2000 with planning the research project and assigning project staff to applicable duties and tasks. Other key objectives associated with Phase I included: a) designing and conducting the focus groups, b) finalizing the survey instrument, and c) finalizing the study's methodology. Deliverables for this phase of the research project included a written report on the focus groups, the design of the final survey instrument, and quarterly reports to AHCCCS and the Flinn Foundation. Phase I ended in July 2000.

Phase II of the project began in July 2000 and was completed in February 2001. Phase II consisted of conducting the baseline survey for ALTCS consumers. Feedback was provided to AHCCCS after the first 100 respondents completed their interviews. Demographics, frequency distributions, and proposed modifications to the telephone interview were summarized and discussed with AHCCCS. Objectives for the survey consisted of: a) programming the computerized phone system with the survey, b) training phone interviewers, c) establishing procedures for interviews and for monitoring the interviewers, d) developing criteria for the proxies, e) conducting the survey, and f) analyzing and reporting the findings. Deliverables for this phase of the research project included a report on the first 100 survey respondents, quarterly reports to AHCCCS and the Flinn Foundation, and a series of reports representing Phase II survey findings, "Baby Boomer" focus group findings, and policy recommendations resulting from Phase II survey findings.

Phase III of the project began in February 2001 and ended in September 2001. This phase consisted of re-interviewing the initial respondents by telephone and interviewing new respondents with the survey tool. An analysis was conducted comparing those respondents who changed health plans versus those respondents who did <u>not</u> change

health plans on satisfaction with long term care services. Deliverables for Phase III included a series of reports representing Phase III survey findings, policy considerations resulting from Phase III survey findings, and quarterly reports to AHCCCS and the Flinn Foundation.

D. Steering Committee

At the onset of the project, a Steering Committee was created to provide necessary oversight and guidance to AHCCCS and HSAG. The Steering Committee consisted of staff from both organizations, as well as from the Flinn Foundation (the funding source) and from the Arizona State University (ASU) team responsible for implementing the telephone survey. Three subcommittees—Advisory Panel, Research, and Data—were also created to provide specific guidance on matters relating to either the research methodology or data collection methods and techniques. The role of the subcommittees was viewed as central to the overall management of this project, considering the tight timeline under which all teams worked. Each subcommittee had a chairperson and was composed of representatives from each of the participating organizations.

E. National Advisory Panel

A National Advisory Panel was assembled to work with the Steering Committee. Members of the panel were selected by the Flinn Foundation and AHCCCS and represented experts in the fields of long term care, gerontology, sociology, and survey design and implementation. At key stages of the project, the National Advisory Panel provided advice and/or assistance to the various subcommittees, with emphasis in working with the Research Subcommittee. The major duties associated with appointment to this Advisory Panel included review of the survey instrument, review of the research methodology used in the "Baby Boomer" focus group, review of the interim survey result report, and review of the final (2002) survey result report. For a more complete description of the members of the National Advisory Panel, please see Appendix B.

II. SURVEY DEVELOPMENT

A. Re-Measure of Survey Instrument

Based upon Phase II survey results and the original research questions, it was necessary to revise the survey instrument for Phase III. This was done in order to include questions pertaining to reason why member changed health plan, proxy/consumer relationship and to refine the cultural needs question. In addition to determining how many consumers changed health plans, it was also recommended that a question be written to measure why a consumer elected to change or not change their health plans. Therefore, several questions were written to measure why a consumer chose the health plans selected during Phase III, including a menu whereby consumers selected all applicable reasons for changing health plans. Questions were also written to measure whether or not a consumer was satisfied with their new health plan in comparison to their old health plan.

During Phase II, the cultural needs question posed great difficulty in terms of consumers' comprehension of the question. In an effort to correct the problem, an additional literature review was conducted. The findings resulted in the cultural needs question being rewritten for greater clarity.

Finally, to better understand the relationship between proxy and consumer, additional questions were designed to measure the relationship between these individuals. HSAG and ASU worked together to finalize the wording of the questions and the interview script based upon the above changes. Phase III interviews began in mid-June with the newly modified survey instrument.

In the follow-up interview phase, AHCCCS, ASU, and HSAG determined that the proxy files had been updated to the best of their ability and the likelihood that the new health plans would have additional information pertaining to proxies was unlikely. It was believed that the time between health plans submission of proxy information and the start of the interview phase was short and changes in records would be minimal. (Appendix B contains the revised survey instrument used in Phase III. After each survey question is an "identification tag" of which source was used for the given question).

B. Spanish Version Of Tool

As in Phase II, the modified survey tool was translated into Spanish by ASU and tested to ensure that the translation from English to Spanish did not change the contextual meaning of any questions. The procedure for utilizing the Spanish version of the tool was as follows: When a call was made and the interviewer determined that the consumer or proxy could speak only Spanish, arrangements were made for an interviewer who was fluent in Spanish to call the individual back at a later time and conduct the survey using the Spanish version of the tool. This procedure was followed throughout Phase III.

C. Pre-Testing Phase

Programming the Computer Assisted Telephone Interview (CATI) with the survey questions, rehearsal of the script by the interviewers and pre-testing of the survey instrument was immediately begun by Arizona State University Survey Research Laboratory (ASU/SRL) following final approval of the modified survey tool. While the CATI instrument was being programmed, the interviewers who had been trained for the project rehearsed with paper copies of the survey script to familiarize themselves with the wording of the questions and the skip pattern of the questions. Once the CATI instrument was programmed, the interviewers practiced using the CATI equipment and the programmed script. During practice sessions, feedback was provided by the ASU/SRL Supervisor, thus enhancing reliability of the survey instrument.

After the first 100 respondents completed the interview, ASU staff prepared a report for HSAG and AHCCCS. Excluding the “proxy issue” (addressed below), there were no substantial issues detailed in the "First 100 Responders" report. HSAG did recommend, and it was accepted, changing the reason for a change in health plans to an open-ended question. After reviewing data from the first 100 responders, it was determined that the questions were working well with respect to clarity and length of time.

As with Phase II, the majority of the data obtained during pre-testing, however, related to how and when to contact respondents (i.e., disconnected or missing phone numbers or no proxy listed and consumer unable to answer questions). As a result of these findings, a procedure was established with health plans for researching erroneous phone numbers and missing proxy information. The procedure that was developed was utilized throughout the remainder of the survey.

III. SURVEY IMPLEMENTATION

A. Training Of Interviewers

As with Phase II, before interviewers in Phase III were permitted to conduct telephone interviews for the LTC Consumer Satisfaction Survey Project, they were required to attend a half-day training session on the project. The training session covered the purpose of the project, terminology and definitions commonly used in long term care and Medicaid, advanced interviewing techniques, phone equipment, the survey tool, and the required documentation. The majority of the interviewers had previous experience with telephone surveys and demonstrated a good knowledge of and skills in telephone interviewing techniques.

Administrative staff from ASU/SRL conducted training sessions to familiarize interviewers with the survey process. During these sessions, each interviewer was given a manual containing reference materials for the project and general SRL policies and procedures. Once the interviewer had attended a training session, they conducted "practice" interviews in the laboratory with the phone equipment and the survey script. Administrative staff from ASU/SRL provided verbal feedback to the interviewers during the practice sessions providing an avenue for increasing interrater reliability.

Upon satisfactory completion of the phone training, interviewers were scheduled to work on the project. Interviewers continued to utilize the manual as a reference guide when questions arose during the interview process. Along with basic AHCCCS terminology, the names and telephone numbers of key project personnel from AHCCCS, HSAG and ASU were posted in each interviewer's cubicle for easy reference during calls.

B. Establishing Procedures

In order to maintain consistency between the two surveys, procedures were established. Procedures covered issues pertaining to the number of call attempts, the number of callbacks, confidentiality, criteria for proxies, and unavailability of residents at nursing homes. Correct use of established procedures were addressed during training and practice sessions.

During Phase II the use of face-to-face interview was eliminated. This was done for three reasons: First, the need to eliminate face-to-face interviews centered on the fact that telephone interviews and face-to-face interviews were two separate methodologies. Each methodology affected the individual's response in very different ways and had the potential to skew results. Use of only one methodology was preferred. Second, there was a need to ensure the participation of cognitively alert nursing home residents in the study. Because cognitively alert residents were able to participate in the study by telephone in a quiet and private place within the nursing home, face-to-face interviews were not necessary. Third, there were no situations in which lack of confidentiality or privacy required face-to-face interviews.

C. Method Of Researching Incorrect Phone Data

As with Phase II, although to a much lesser degree, the issue of incorrect telephone data arose in Phase III. The same procedure established during Phase II was adopted for Phase III. It was determined that some of the telephone numbers for consumers and proxies had changed, or the condition of the consumer had deteriorated and now a proxy was making decisions on their behalf. Because of these data issues, a procedure was developed with the ASU/SRL Director and the three (3) health plans. The procedure required the ASU/SRL Director to send an electronic list weekly to the health plans of incorrect or disconnected telephone numbers and incorrect or missing proxy names for consumers who were no longer cognitively intact. Since health plans staff were required to conduct an assessment of their consumers every three to six months, their database was the most current automated system. Numbers and names were researched with the assistance of a staff member and sent back to ASU.

D. Criteria For Proxies

As always, the consumer, who was the recipient of LTC services, was the preferred respondent. However, during Phase II it was found that 73 percent of the consumers were unable to speak for themselves because of a cognitive impairment. In cases in which consumers could not speak for themselves, the Research Team decided that a proxy would be interviewed. In the cases in which a consumer had a legal guardian, the guardian would be interviewed. The number of consumers with legal guardians was relatively small and very easy to determine. There were frequent instances where the family member was both their caregiver and proxy. In this case, the family member was interviewed as the proxy and caregiver questions on the survey were skipped. If the interviewer had any concerns about who the proxy was, the cases were referred to the health plans for research and follow-up.

The frequency of interactions/visits between the consumer and the proxy continued to be an important consideration in Phase III. The level of the proxy's involvement with the consumer helped determine how well the proxy knew the consumer and whether he or she could answer questions about their care. In addition to the question regarding proxy involvement, added during Phase II, questions regarding proxy demographics were added in Phase III.

E. Monitoring Interviewers And Phone Interview Process

Throughout the telephone interview process, an ASU/SRL Administrative staff member was present in the SRL and monitored all interviewers at periodic intervals. Overall, a 10 percent sample of all calls placed by each interviewer was monitored. The interviewer was evaluated using the standardized monitoring form that was used during the initial training session. When the ASU/SRL Administrative staff observed any significant issue, the situation was immediately addressed by the supervisor. No serious issues were reported. Minor issues (i.e., modulation of voice) were discussed with the interviewer

after the completion of the call, and a periodic follow-up was done to ensure that the issue had been corrected. All monitoring was documented in writing.

The ASU Survey Research Laboratory conducted the consumer telephone survey interviews from mid-June through September 30, 2001. ASU conducted daily monitoring of interviewers to ensure collection of required information and provided feedback to the interviewer. Moreover, ASU provided reports detailing the weekly status of interviews for respondents in the home and community-based services (HCBS) and nursing facilities (NF). Oversight of the telephone interviews, conducted by ASU, was periodically monitored by HSAG in Phase III to ensure compliance with established procedures.

IV. METHODS

A. Survey Respondents

Survey respondents consisted of two groups of EPD individuals. The first group was aged 18 to 64 years and the second group was 65 years and older and both groups were enrolled in the ALTCS program for a minimum of one year. Spouses, other family members, or legal guardians (referred to as proxies throughout this research report) responded to the survey on behalf of the consumer who suffered from a cognitive impairment. Finally, the group was divided into: 1) those persons residing in home and community-based settings (home, adult foster care, and assisted living), 2) those persons residing in a nursing facility; as well as: 3) those who changed health plans, and 4) those who did not change health plans.

B. Measures

The survey in Phase III measured seven areas: 1) miscellaneous—health status; 2) satisfaction with case managers; 3) satisfaction with doctors; 4) satisfaction with HCBS caregiver; 5) satisfaction with NF caregiver; 6) proxy demographics, and 7) administrative that covered a) reason for health plan selection, b) improving long term care, and c) whether consumers live alone. Measures are analyzed according to the following stratifications: those who changed health plans, gender (no differences were reported; therefore, this stratification was dropped), age grouping (18-64 versus 65 and older), respondent (proxy versus consumer), and placement (HCBS versus NF).

To assess self-reported health status of ALTCS survey respondents, two questions from the SF-12 Health Survey were incorporated into the survey. The case manager, doctor, and caregiver items were adapted from CAHPS®, Patient Satisfaction Questionnaire (PSQ), the Non-Medical Home and Community-Based Services Customer Satisfaction Survey 1999, the 1999 MIHS LTC Nursing Home Consumer Survey, the AHCCCS Acute Care Survey, plus the addition of several original questions written by the Research Team. Finally, qualitative data were collected from survey respondents to further describe the perspectives of consumers in measuring satisfaction and dissatisfaction of case managers, doctors, and caregivers in both the HCBS and nursing facility environments, and change of health plan.

C. Sample Methodology

Eligible Population

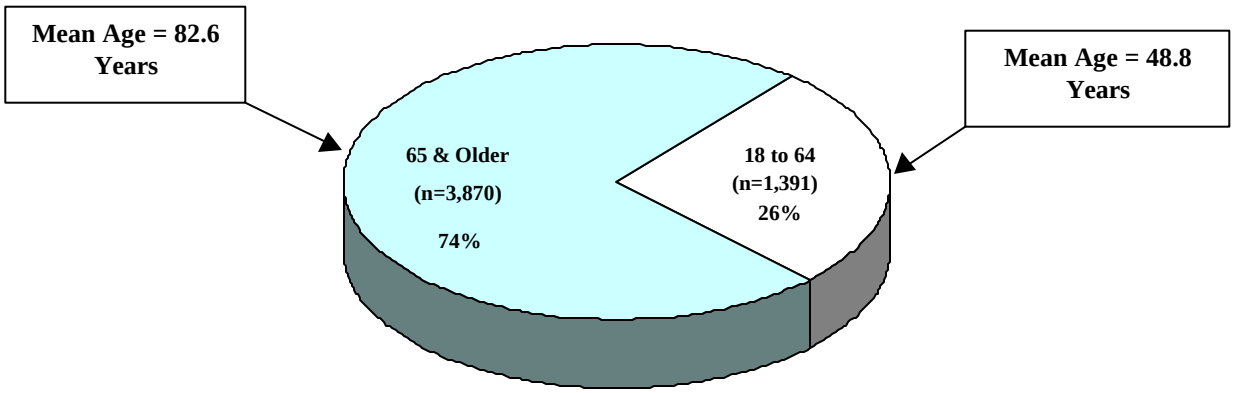
The final eligible population for the 2000 survey was 6,925 consumers. As of May 2001, approximately 24 percent (1,664) of the eligible population had either died or were no longer eligible. Therefore, the final eligible population for the 2001 survey was 5,261 consumers.

AHCCCS provided the database of 5,261 members who met the eligibility criteria to HSAG. The eligibility criteria included members who were 18 years of age or older, were continuously enrolled in the ALTCS program for at least one year with no more than a

one-month (i.e., 30 days) gap in enrollment, and were currently enrolled in the program, see Figure 1.

Figure 1

Distribution of Age
Total Eligible Population of 5,261



Overall Mean Age = 73.7 Years

Sample Selection

The sample selected for the 2001 survey consisted of those members from Phase II who were still eligible for inclusion in the study and those individuals who recently enrolled in an AHCCCS health plan. The two main populations of members in a nursing facility (NF) and those in a home or community based setting (HCBS) were maintained. As was the age group representations of 18-64 and 65 and older. Since the number of members who changed health plans was small (352, or about 7 percent), they were all included in the sample regardless of being contacted in Phase II or not.

A final sample size of 1,413 members was drawn for the survey. The eligible population distribution showed 52 percent were in a NF and 48 percent were HCBS. The distribution by age group for the eligible population was 26 percent in the 18 to 64 years of age group, and 74 percent 65 years and older. The initial sample of 1,413 (or 26.9 percent of the eligible population) was designed to account for mortality and non-response (including an over-sample for consumers in the 18 to 64 years of age group) and is displayed in the table.

Of special note, there was no mechanism available to control for consumers who participated in both survey years (n= 581) and who may have switched from the HCBS

setting to the NF setting between survey years. Thus, if a respondent was in the HCBS setting in survey year one and then switched to the NF setting in survey year two, the respondent was counted in the HCBS setting in survey year one and the NF setting in survey year two.

Sample Size for 2001 Survey

Current Placement	18-64	65+	Total
NF	215	484	699
HCBS	285	429	714
Total	500	913	1,413

Sample Size for Baseline Survey (2000)

Placement	18-64	65+	Total
NF	405	629	1,034
HCBS	314	473	787
Total	719	1,102	1,821

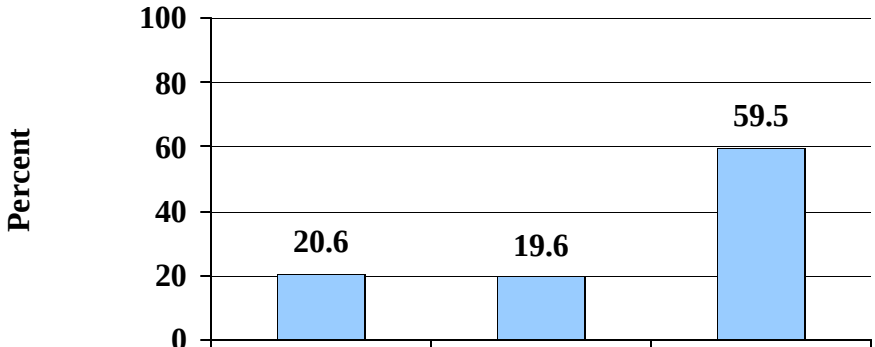
Response Rate

For the survey conducted in 2000, the mortality rate for the ALTCS population was expected to be approximately 10 percent per year, and the survey was expected to yield a 70 percent response rate. The 70 percent response rate was recommended by ASU, with general agreement from AHCCCS based on a prior survey. The surveys were completed by telephone. When a member could not respond, a proxy was surveyed. The final sample size in 2000 consisted of 1,031 respondents, representing a 69 percent response rate. The dropout rate (i.e., mortality or loss of eligibility) for the 2000 survey sample of 1,031 respondents was nearly 13 percent, or 130 members.

The 2001 survey utilized the same methodology, for 1,413 consumers. Only 1,121 consumers were actually eligible for the survey (i.e., 292 consumers either died or lost eligibility prior to the administration of the survey). The response rate for the 2001 survey was 75 percent and had a final sample size of 844 respondents out of the 1,121 eligible members in the sample, see Figure 2.

Figure 2

Response Rates
Original Sample Size = 1,413 or 26.9% of the Eligible Population (N = 5,261)



	Ineligible	No Response	Responded
Percent	20.6	19.6	59.5
Number	292	277	844

Final Response Rate = 844 / (1,413-292 Ineligible) = 75.3%

D. Research Questions

The following questions were identified by the Research Subcommittee as necessary in order to achieve the goals of Phase III of this research project:

1. Is there an overall difference regarding the level of satisfaction for each survey area?
2. Is there a difference between respondents who changed health plans versus respondents who did not change health plans regarding the level of satisfaction for each survey area?
3. Is there a difference regarding the level of satisfaction with case managers, doctors, HCBS, and NF caregivers stratified according to: gender, age grouping (18-64, 65+), respondent (proxy, consumer), placement grouping (HCBS, NF), and those who changed and those who did not change health plans?
4. What demographics describe proxies and their relationships with consumers?

E. Analysis Plan

The primary analysis was conducted on the original stratification as specified in the sampling design. Univariate analyses (aggregate level) are presented, as well as by those respondents who changed health plans. Descriptive statistics, provided in proportions, were used to determine differences in responses based on whether respondents changed health plans. Bivariate analyses for categorical data were computed using the Pearson's Chi Square test. T tests were computed to assess continuous variables.

An underlying question in the study was whether or not (or perhaps to what degree) do proxy responses affect the results. Therefore, responses by proxies were examined and compared to non-proxy respondents. Once again, descriptive statistics, provided in proportions, were used to determine if any differences existed between these groups. Bivariate analyses for categorical data were computed using the Pearson's Chi Square test.

V. DEMOGRAPHICS AND SAMPLING

A. Age/Placement

There were a total of 844 respondents participating in the Phase III survey. Of the total respondents, 51 percent lived in the home and community, while 49 percent lived in a nursing facility. Of those living in the community, 23 percent lived alone, while 34 percent lived with someone else, and 44 percent lived with their proxy. The overall mean was 70.8 years of age, which is just one year older than the population in Phase II. The majority of survey respondents were in the 65 and over age group. However, when each group was analyzed individually, the mean age in the 18 to 64 age group was 49.9 years of age (one year younger than the population in Phase II), and the mean age in the 65 years of age and older was 82.8 years of age (equal to that of the population in Phase II), both of which are representative of the ALTCS population.

B. Gender

Literature sources indicate that the majority of individuals receiving long term care through Medicaid are female. Further, the literature indicates that 70 percent of caregivers (or proxies) are female. It was important to determine if statistics for respondents in the Phase III survey were reflective of the statistics in the literature. Of the 844 individuals participating in the Phase III survey, 66 percent of the respondents were female. Gender of the respondents was further analyzed based on whether the respondent was a consumer or a proxy. Females were represented in greater proportions for both consumers and proxy categories. Consumer respondents were comprised of 62 percent females (n=126) and 38 percent males (n=76). Proxy respondents were comprised of 67 percent females (n=430) and 33 percent males (n=212). Since no statistical differences were found on the stratification of gender, it was eliminated from the remaining analysis.

C. Race/Ethnicity

Data were also analyzed according to race/ethnicity in order to determine if the respondents for this survey were similar in composition to the races within the ALTCS program in Arizona. The racial/ethnicity background for the majority of both consumers (78 percent) and proxies (76 percent) was White. Hispanics represented 11 percent of consumer respondents and 15 percent of proxy respondents. African Americans consisted of 7 percent of consumer respondents and 6 percent of proxy respondents, while Native Americans consisted of 0.5 percent of consumer respondents and 1 percent of proxy respondents. The race/ethnicity for this project was similar in composition to the ALTCS program in Arizona. Again, since no statistical differences were found on the stratification of race/ethnicity, it was eliminated from the remaining analysis.

VI. GENERAL CHARACTERISTICS

A. Understanding Questions

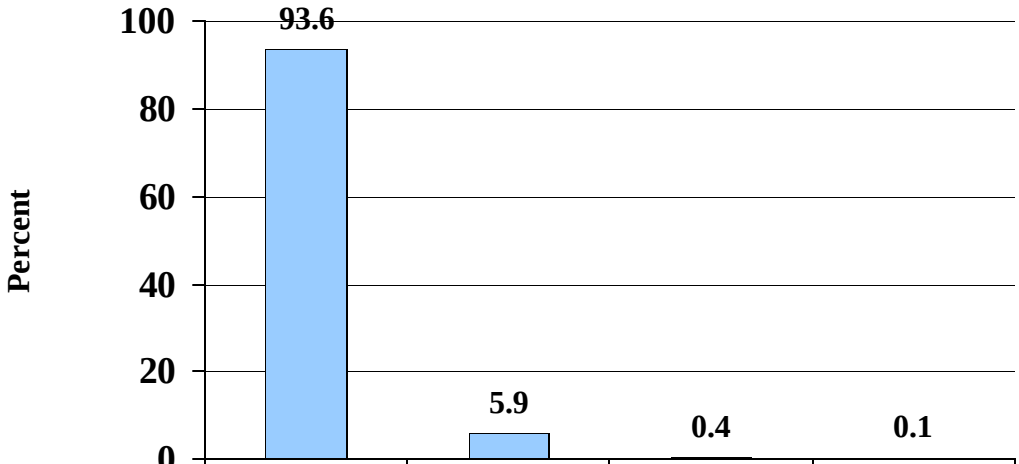
According to interviewers, the majority of respondents (consumer and proxy) understood all or almost all of the questions. Interpreters were available to address language problems and interviewers adjusted telephone volume to assist individuals in completing the survey.

Respondents answered most of the questions asked on the Phase III survey tool, Figure 3. Questions about cultural needs were answered more frequently in the Phase III survey period than in Phase II. Some consumers (or proxies) chose not to answer certain questions. In these instances, the survey was still considered valid, but the respondent was removed from the denominator for that particular question. Finally, a few of the questions had too few responses to be meaningful and, therefore, are not presented in this report.

The footnote for each graph may or may not include a reference to a "p-value." This is displayed only when there is a statistical difference between the specified category (e.g., those who changed health plans versus those who did not change health plans). A p-value below 0.05 is considered to be statistically significant.

As previously indicated, the survey measured seven areas: 1) miscellaneous—health status; 2) satisfaction with case managers; 3) satisfaction with doctors; 4) satisfaction with HCBS caregiver; 5) satisfaction with NF caregiver; 6) proxy demographics, and 7) administrative that covered, a) reason why member changed health plan, b) improving long term care, and c) whether consumers live alone. For each of the survey areas, aggregate (overall) results are provided, followed by a comparison to those who changed and those who did not change health plans, then followed according to the following stratifications: age grouping, respondent (proxy versus consumer), and placement (HCBS versus NF). The primary scale used throughout the survey was a Likert Scale that ranged from very satisfied to very dissatisfied.

Figure 3
Interviewer's Rating of Respondent
Total Respondents = 844



	Understood All or Most	Difficulty with Some Questions	Difficulty with at Least 10 Questions	Lots of Difficulty
Percent	93.6	5.9	0.4	0.1
Number	790	50	3	1

B. Proxy Involvement

As was determined during Phase II, proxies can provide meaningful information to Arizona's long term care system. Phase II results clearly showed that, in many situations, proxies are important caregivers of long term care services for their family or friends. Given these survey results, the Research Subcommittee developed additional survey questions to further understand the proxy relationship with consumers.

The total number of respondents participating in the Phase III survey was 844. Of this total, 202 (24 percent) were consumers and 642 (76 percent) were proxies (Figure 4). For purposes of this study, proxies were defined as those individuals who speak on behalf of a cognitively impaired consumer who was receiving HCBS or NF services. Cognitive ability of the consumer was determined in two ways. First, AHCCCS provided confirmation regarding the consumer's mental status, as determined by the consumer's case manager during their client assessment. Second, HCBS and NF caregivers were able to validate the cognitive ability of the consumer.

Figure 4

Consumers vs. Proxy Respondents in 2001
n=844

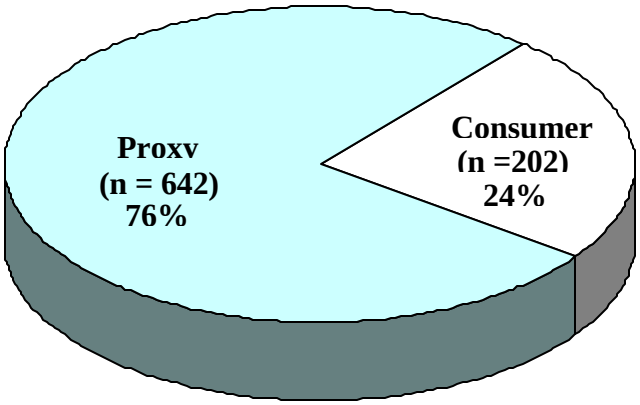
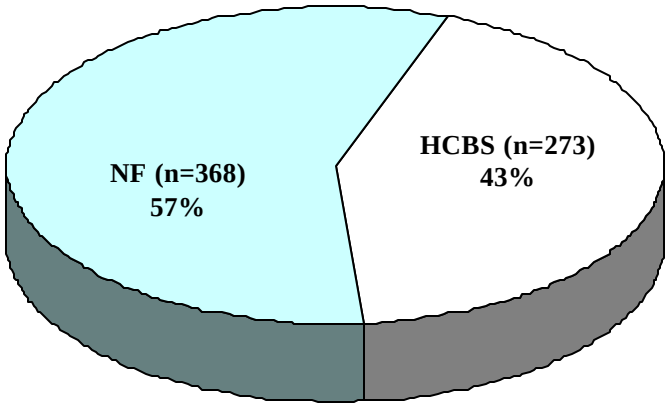


Figure 5

2001
Distribution of Proxy Respondents
By Placement
n=641



Proxy Age and Location

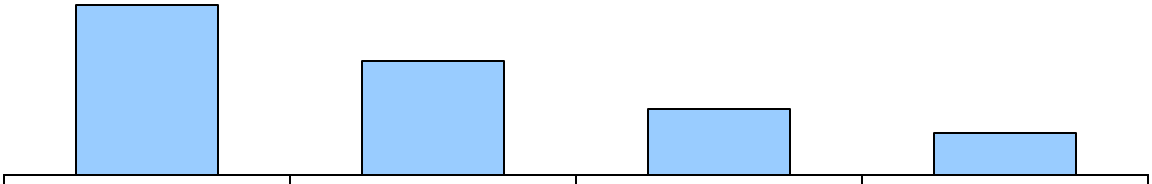
The mean age of proxies was 57 with a range of 26 to 96 years old. Proxies live predominantly in the Maricopa County area (88 percent, n=447). Five percent (n=26) live somewhere else in Arizona and 7 percent (n=36) of proxies live out-of-state. Of the 642 proxies who responded to this survey, 368 (57 percent) represented consumers living in nursing facilities and 275 (43 percent) represented consumers living in a community setting (see Figure 5).

Proxy Involvement

The degree to which proxies are involved with a consumer was measured to determine how involved a proxy was in knowing the various caregivers providing services to the consumer. As indicated, seventy-two percent of proxy respondents were involved either daily or a few times a week with their family member, friend, or court-appointed consumer, Figure 6. The high rate of proxy involvement allowed the Research Team to analyze proxy data with a reassured comfort level regarding how well proxies are involved with consumers.

Figure 6

Proxy Involvement with Consumers

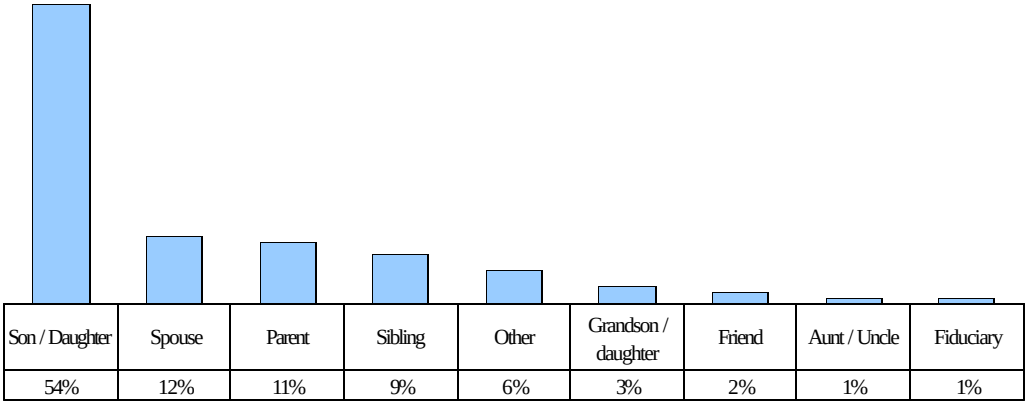


Type of Relationship

Among the additional Phase III survey questions asked of proxy respondents was the question of what type of relationship they had with the consumer. More than half of proxy respondents reported that they were either the son or daughter of the consumer (54 percent), followed by spouse (12 percent), parent (11 percent), and sibling (9 percent). The relationship categories are depicted in Figure 7.

Figure 7

Proxy Relationship with Consumers



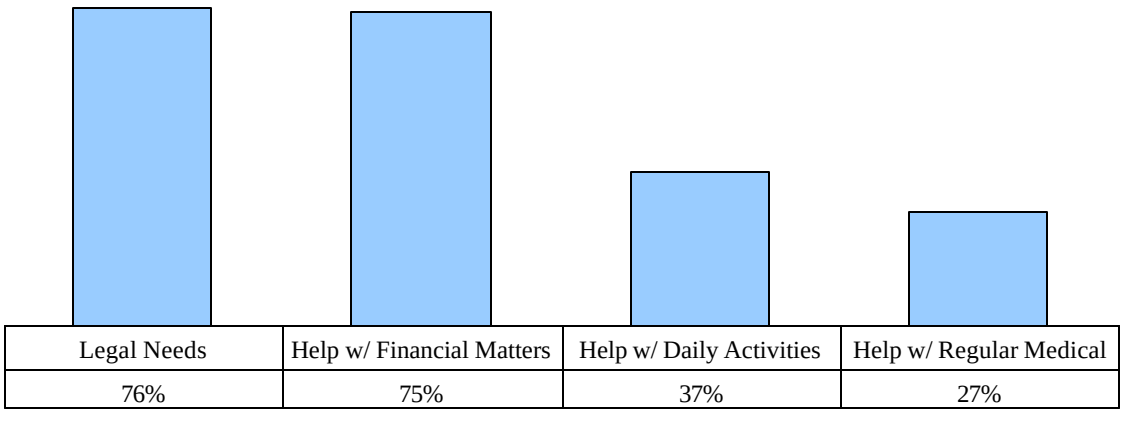
Notes: Due to rounding, percentages do not always add to 100%.

Support Provided by Proxies

Proxy respondents were also asked to describe the type of support they regularly provide to long term care consumers. The top two services provided by proxies were legal (76 percent) and help with financial matters (75 percent). Support services provided by proxies are depicted in Figure 8.

Figure 8

Proxies Support Consumers



Note: Respondents who answered question depicted in Figure 8 were allowed to select more than one answer.

C. Health Status

Overall, 67 percent of respondents rated their current health as either fair or poor. The rate was slightly higher for those who changed health plans (71 percent) and slightly lower for those who did not change health plans (66 percent).

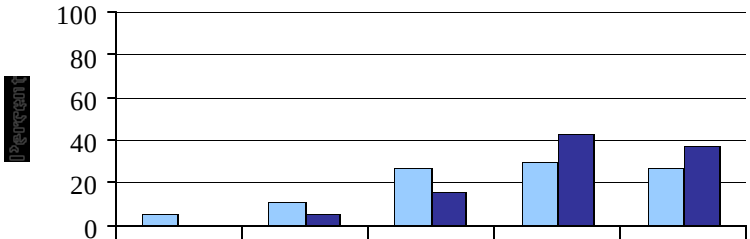
For those who changed health plans, statistical differences were noted between age grouping and consumer – proxy respondent concerning current health status. Respondents aged 65+ were more likely to rate the consumer's current health as either fair or poor (80 percent) than respondents aged 18 – 64 (57 percent), see Figure 9. Proxy respondents were more likely to rate their current health as either fair or poor (75 percent) than consumer respondents (63 percent), see Figure 10.

Overall, 43 percent of respondents rated their health compared to one year ago as about the same. The rate was identical for those who changed health plans (43 percent) and slightly higher for those who did not change health plans (44 percent).

For those who changed health plans, statistical differences were noted between age grouping. Respondents aged 18-64 were more likely to rate their health compared to one year ago as about the same (51 percent) than respondents aged 65+ (38 percent), see Figure 11.

Figure 9

For Those Who Changed Health Plans, Health Status by Age Grouping

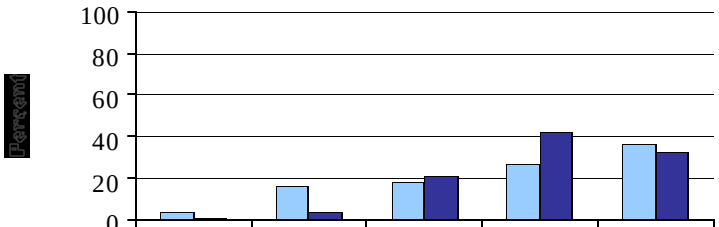


	Excellent	Very	Good	Fair	Poor
18-64	5	11	27	30	27
65+	0	5	16	43	37

Notes: Not all questions were answered by all respondents. Results by age group are statistically different with a p-value = 0.014. Due to rounding, percentages do not always add to 100%.

Figure 10

For Those Who Changed Health Plans, Health Status by Respondent

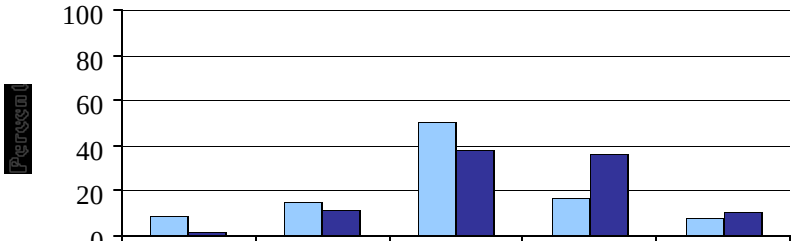


	Excellent	Very Good	Good	Fair	Poor
Consumer	4	16	18	27	36
Proxy	1	4	21	42	33

Notes: Not all questions were answered by all respondents. Results by age group are statistically different with a p-value = 0.022. Due to rounding, percentages do not always add to 100%.

Figure 11

For Those Who Changed Health Plans, Health Status Compared to One Year Ago by Age Grouping



	Much Better	Somewhat Better	About the Same	Somewhat Worse	Much Worse
18-64	9	15	51	17	8
65+	2	12	38	36	11

Notes: Not all questions were answered by all respondents. Results by age group are statistically different with a p-value = 0.015. Due to rounding, percentages do not always add to 100%.

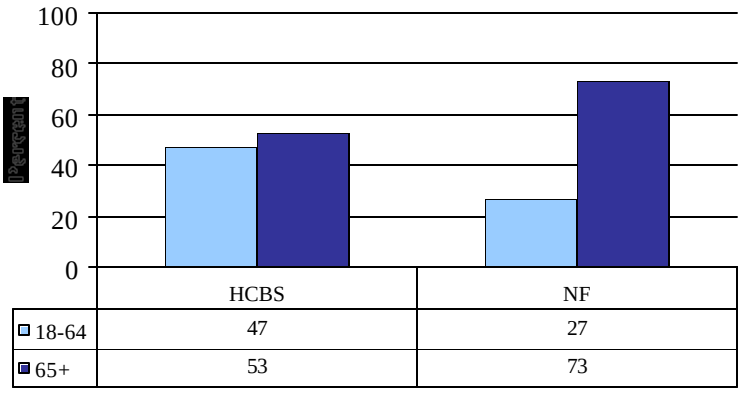
D. HCBS versus Nursing Facility

Overall, 51 percent of respondents lived in HCBS and 49 percent lived in NF. The rate was similar for those who changed health plans (53 percent HCBS and 47 percent NF) compared to those who did not change health plans (50 percent HCBS and 50 percent NF).

For those who changed health plans, statistical differences were noted between the age groupings. Of those respondents living in the HCBS setting, more respondents aged 65+ were living in this setting (53 percent) than respondents aged 18 – 64 (47 percent). Of those respondents living in the NF setting, more respondents aged 65+ were living in this setting (73 percent) than respondents aged 18 – 64 (27 percent), see Figure 12.

Figure 12

For Those Who Changed Health Plans, Current Placement by Age Grouping



Notes: Not all questions were answered by all respondents. Results by age group are statistically different with a p-value = 0.06. Due to rounding, percentages do not always add to 100%.

VII. SURVEY RESULTS, COMPARISONS BETWEEN 2000 AND 2001

In 2000, AHCCCS asked current ALTCS consumers if AHCCCS was taking care of long term care business. Overall, survey results indicated that consumers were very satisfied with their providers' case manager, doctor, HCBS caregiver and NF caregiver. After consumers had the opportunity to change health plans, consumers were again surveyed in 2001 and the results from this time period were compared to the 2000 results. Across all areas, case manager, doctor, HCBS and NF caregivers, respondents reported a high level of satisfaction in both survey years.

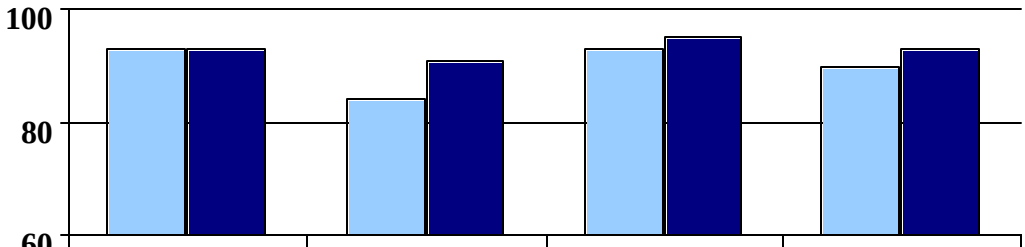
Since the differences between survey year 2000 and 2001 were minimal, the Research Team decided to focus on the results between those who changed health plans and those who did not change health plans.

As depicted in Figure 13, the doctor, HCBS, and NF areas all reported increases in the overall level of satisfaction between survey year 2000 and 2001. However, the case manager area did not show an increase in the level of overall satisfaction.

For the doctor area a statistical difference was noted between 2000 and 2001, with an increase of 7 percent in the overall level of satisfaction. Additional measures within the doctor area also realized a statistical difference between 2000 and 2001. For example, doctor's listening skills, doctor's helping consumers when needed, doctor's involving consumers, and doctor's consideration of consumers' cultural needs all increased in satisfaction ratings between 2000 and 2001.

The HCBS caregiver area showed an increase in overall satisfaction rating of 2 percent between 2000 and 2001, while NF caregiver showed an increase in overall satisfaction rating of 3 percent between 2000 and 2001.

Figure 13
Overall Satisfaction on Survey Domains Between Survey Years



	Case Manager	Doctor	HCBS Caregiver	NF Caregiver
2000	93	84	93	90
2001	93	91	95	93

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-0.000). Due to rounding, percentages do not always add to 100%.

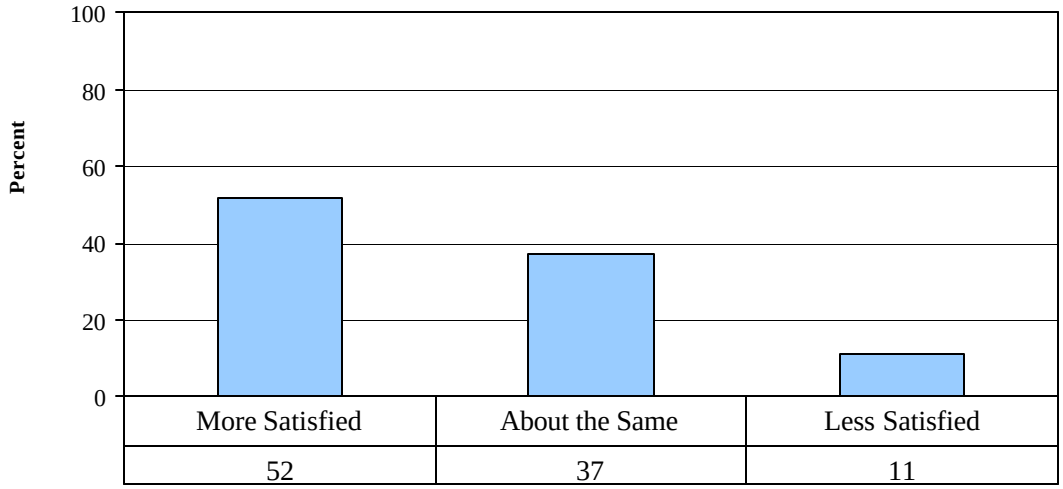
VIII. SURVEY RESULTS BASED UPON WHETHER A CONSUMER CHANGED HEALTH PLANS

The second question asked of consumers in survey year two was whether there was a difference in how consumers reported the level of satisfaction with providers based on whether they changed health plans.

Survey respondents were asked a series of questions to determine the satisfaction ratings of consumers or proxies with caregivers involved in delivering long term care services. Overall results for 2001 are first presented. Then, all research questions are stratified based on whether a consumer changed health plans or did not change health plans. Next, research questions are stratified according to age categories (18 to 64 years of age, 65 and over), placement (HCBS, NF), and type of respondent (consumer, proxy).

Figure 14

Satisfaction Among Consumers Who Changed Plans Health Plans, New Plan Compared to Old Plan



Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-0.000).

A total of 174 respondents out of the 844 respondents who participated in Phase III changed their health plans during the open enrollment period from October through December of 2000. No statistical differences were detected for gender or race/ethnicity between those who changed health plans and those who did not change health plans. Of those who changed health plans, 52 percent reported that they were more satisfied with their new plan when compared to their old plan, while 37 percent of those who changed health plans reported that their satisfaction level between the health plans remained the same. Finally, of those who changed health plans 11 percent reported being less satisfied with their health plan (see Figure 14).

Of those who changed health plans, 64 percent changed plans on their own while 36 percent of respondents required help from someone. The reason respondents cited most often for wanting to change health plans was location of the hospital (cited by 35 percent of respondents, n=60), quality of hospital (cited by 29 percent of respondents, n=33), quality of doctor's services (cited by 28 percent of respondents, n=49), and location of doctor (cited by 22 percent of respondents, n=39).

A. Satisfaction With Case Manager

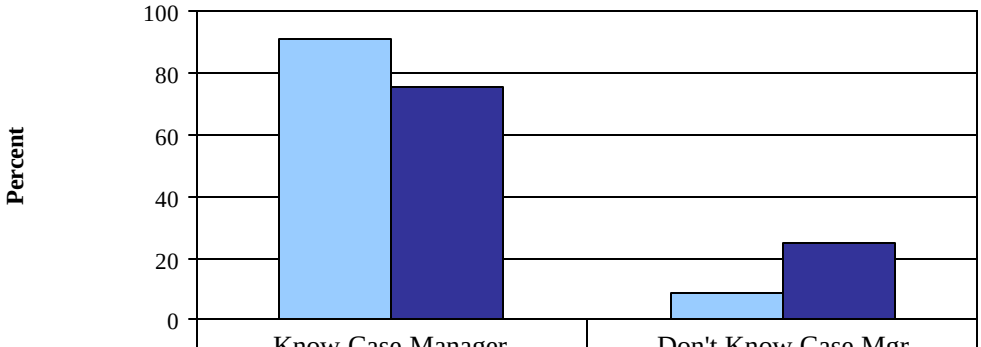
As previously reported, the level of satisfaction across all areas was high between the two years. Therefore, the research team decided to focus on those who changed and did not change health plans.

Knowing Ones' Case Manager

Overall, 76 percent of all respondents knew their case manager. Seventy-nine (79) percent of respondents who changed health plans knew their case manager, while 76 percent of those who did not change health plans knew their case manager.

Figure 15

Those Who Changed Health Plans and Know Case Manager, by Respondent



	Know Case Manager	Don't Know Case Mgr
Consumer	91	9
Proxy	75	25

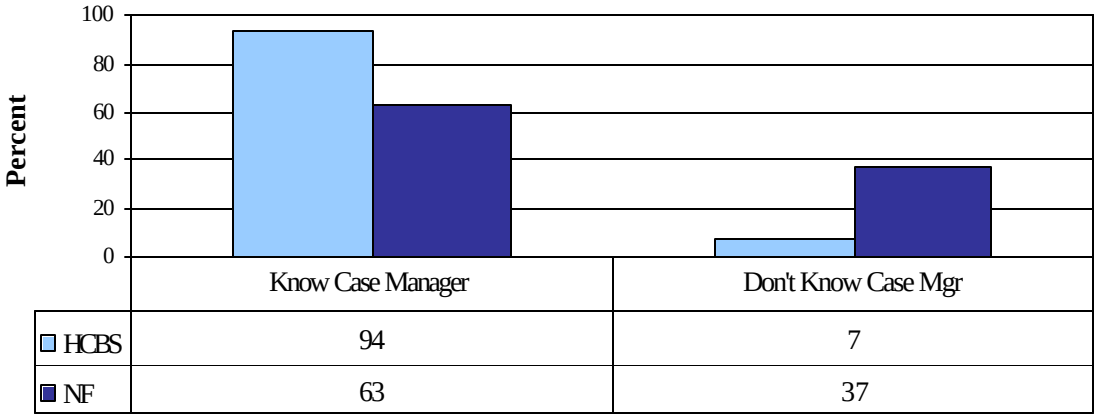
Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.
Results by current placement are statistically different with a p-value = 0.023.

For respondents who changed health plans, statistical differences were found between consumer and proxy respondents and between HCBS and NF placement in regard to

knowing the case manager. Consumer respondents were more likely to know their case managers (91 percent) than were proxy respondents (75 percent), please see Figure 15. HCBS respondents were more likely to know their case manager (94 percent) than were NF respondents (63 percent), please see Figure 16.

Figure 16

Those Who Changed Health Plans and Know Case Manager, by Placement



	Know Case Manager	Don't Know Case Mgr
HCBS	94	7
NF	63	37

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-0.000).

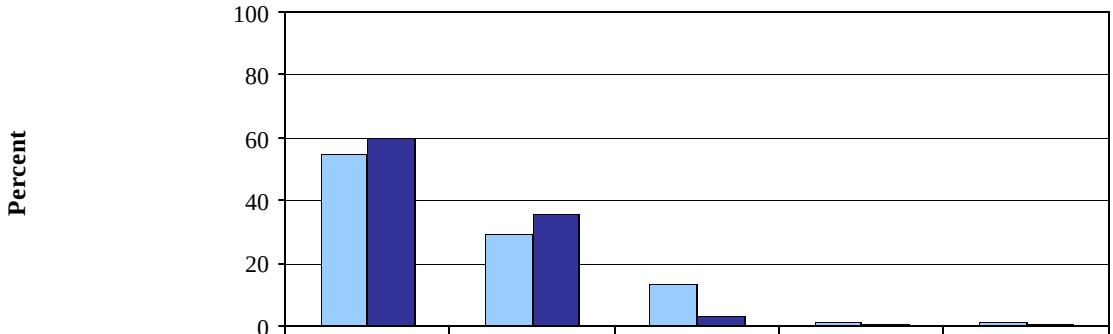
Overall Satisfaction

Overall, 93 percent of all respondents report being very satisfied to satisfied with their case managers. There was a significant difference found between those who changed and did not change health plans concerning the overall level of satisfaction with case managers. Respondents who did not change health plans were more satisfied with their case managers (96 percent) than were those who did change health plans (84 percent), see Figure 17.

There were no statistical differences found between age groups, consumer and proxy respondents, and current placement for those who changed health plans concerning their overall level of satisfaction with case manager.

Figure 17

Overall Satisfaction for Case Managers, by Those Who Changed and Those Who Did Not Change Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plan	54.7	29.2	13.1	1.5	1.5
Did Not Change Health Plan	59.6	35.9	3.3	0.6	0.6

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-0.000).

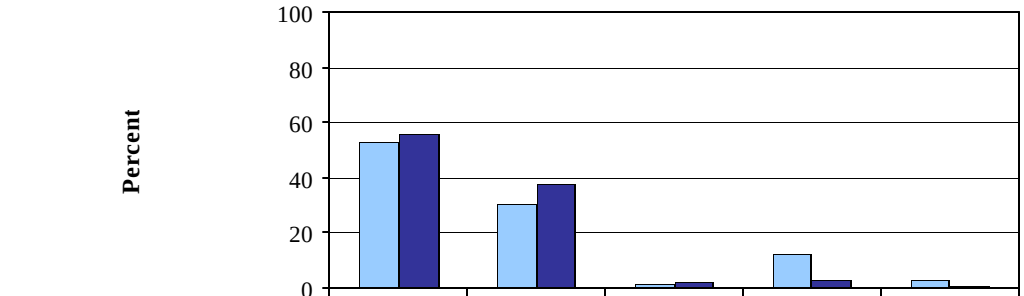
Listening Skills

Overall, 92 percent of all respondents report being very satisfied to satisfied with how well the respondent's case manager listened. There was a significant difference found between those who changed and did not change health plans concerning how well their case manager listened. Respondents who did not change health plans were more satisfied that their case manager listens to them (94 percent) than were those who did change health plans (83 percent), see Figure 18.

There were no statistical differences found between age groups, consumer and proxy respondents, and current placement for those who changed health plans and their satisfaction with their case managers' listening skills.

Figure 18

Satisfaction That Case Manager Listens,
By Those Who Changed and Those Who Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	52.9	30.2	1.5	12.5	2.9
Did Not Change Health Plans	55.5	38	2.4	3.1	1.1

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-0.000).

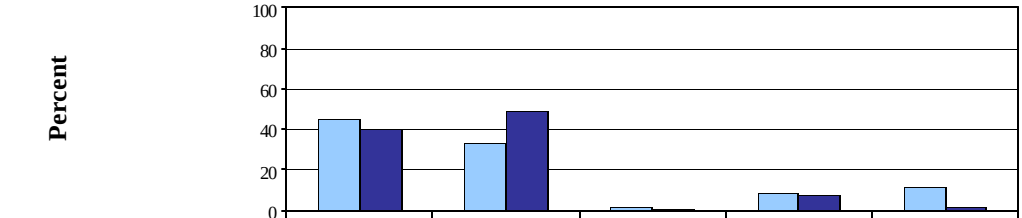
Reaching a Case Manager

Overall, a majority of respondents (87 percent) reported that their case managers were easy to reach. There was a significant difference found between those who changed and did not change health plans concerning their ability to reach their case managers. Respondents who did not change health plans found it easier to reach their case managers (89 percent), while 78 percent of those respondents who did change health plans found it easier to reach their case managers, see Figure 19.

For those respondents who changed health plans, statistical differences were noted between age groups, consumer and proxy respondents, and placement concerning their ability to reach their case managers. Respondents who changed health plans and were aged 65 and over found it easier to reach a case manager (81 percent) than did respondents who were 18 to 64 years of age (74 percent), please see Figure 20. Proxy respondents who changed health plans also found it easier to reach a case manager (86 percent) than did consumer respondents (62 percent), see Figure 21. Finally, 90 percent of NF respondents who changed health plans found it easier to reach a case manager than did HCBS respondents (73 percent), please see Figure 22.

Figure 19

Case Manager is Reachable
By Those Who Changed and Those Who Did Not Change Health Plans

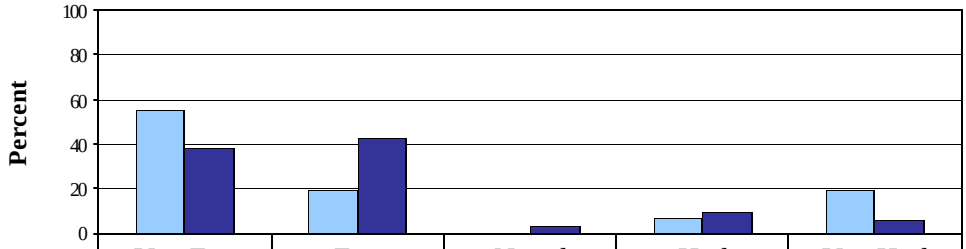


	Very Easy	Easy	Neutral	Hard	Very Hard
Changed Health Plan	44.8	33.3	1.9	8.6	11.4
Did Not Change Health Plan	39.9	49.1	1.2	8.0	1.8

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-value = 0.000).

Figure 20

Those Who Changed Health Plans,
Case Manager Easy To Reach by Age Grouping

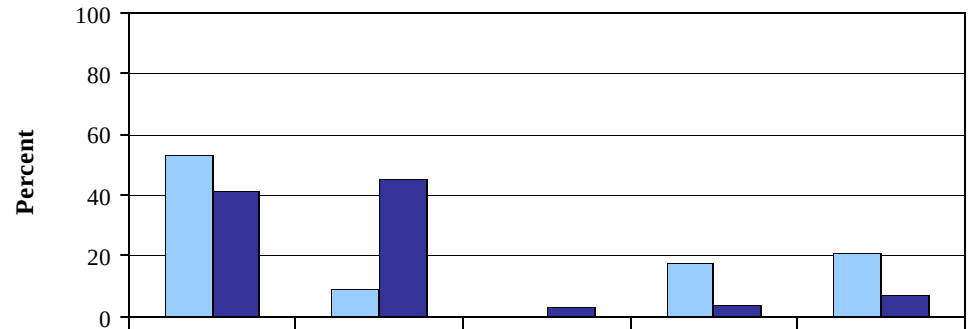


	Very Easy	Easy	Neutral	Hard	Very Hard
18-64	55	19	0	7	19
65+	38	43	3	10	6

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-value = 0.028).

Figure 21

Those Who Changed Health Plans, Case Manager Easy to Reach by Respondent

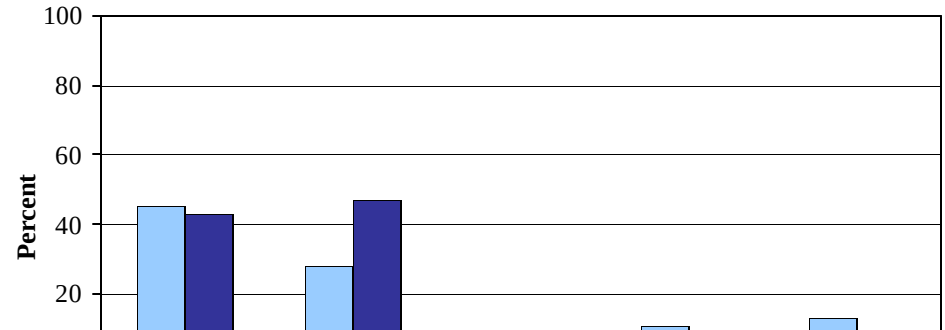


	Very Easy	Easy	Neutral	Hard	Very Hard
Consumer	53	9	0	18	21
Proxy	41	45	3	4	7

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.
Results are statistically different (p-value = 0.028).

Figure 22

Those Who Changed Health Plans, Case Manager Easy to Reach by Placement



	Very Easy	Easy	Neutral	Hard	Very Hard
HCBS	45	28	3	11	13
NF	43	47	0	3	7

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.
Results are statistically different (p-value = 0.000).

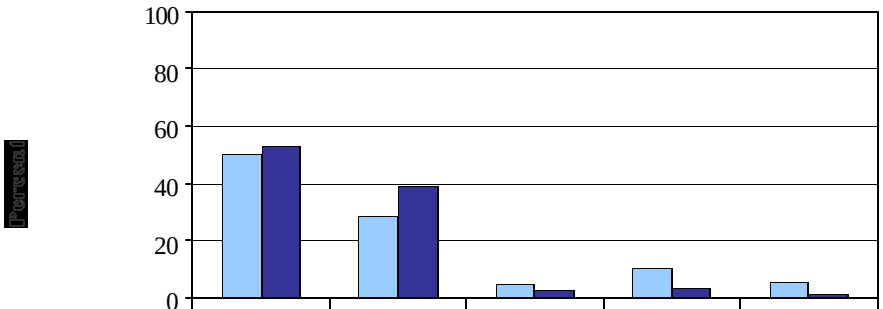
Get the Help Needed

Overall, 89 percent of all respondents reported that they were either very satisfied or satisfied that they get the help needed from case managers. There was a significant difference found between those who changed and did not change health plans concerning the level of satisfaction with getting the help needed from case managers. Ninety-two (92) percent of those who did not change health plans were either very satisfied or satisfied that they get the help needed from case managers; while only 79 percent of those who did change health plans reported that they were either very satisfied or satisfied that they get the help needed from case managers, please see Figure 23.

For those who changed health plans, there were no statistical differences between age groups, consumer and proxy respondents, or placement for this question.

Figure 23

Case Manager Provides Help Needed
By Those Who Changed and Those Who Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	50.5	28.6	4.8	10.5	5.7
Did Not Change Health Plans	53.2	39.1	2.8	3.7	1.2

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-value = 0.002).

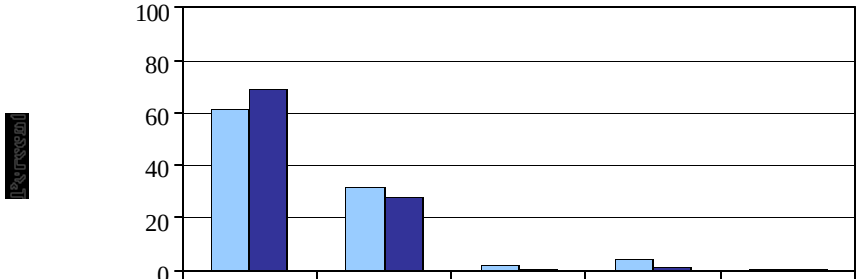
Respecting Consumers

Overall, 96 percent of respondents reported that they were very satisfied to satisfied that their case manager respects consumers. Ninety-three (93) percent of respondents who did change health plans and 97 percent of respondents who did not change health plans were very satisfied to satisfied that their case managers respect consumers, please see Figure 24.

There were no statistical differences for those who changed health plans between age groups, consumer and proxy respondents, or placement for this question.

Figure 24

Case Manager Shows Respect
By Those Who Changed and Those Who Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	61.3	31.4	2.2	4.4	0.7
Did Not Change Health Plans	69.1	28.1	0.9	1.3	0.6

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

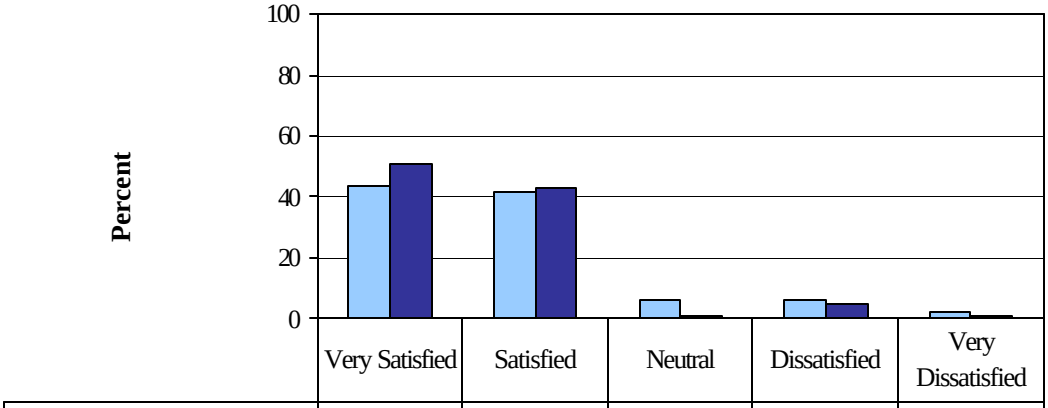
Cultural Needs of Consumers

Overall, 93 percent of all respondents reported that they were either very satisfied or satisfied with how case managers considered the cultural needs of consumers. There was a significant difference found between those who changed and did not change health plans concerning the level of satisfaction regarding how case mangers considered the cultural needs of consumers. Respondents who did not change health plans were more satisfied with how case managers considered cultural needs of consumers (94 percent) than were respondents who did changed health plans (85 percent), please see Figure 25.

For respondents who changed health plans, statistical differences were noted between consumer and proxy respondents and placement on this question. Of proxy respondents who changed health plans, 95 percent were either very satisfied or satisfied with how case managers considered the cultural needs of consumers compared to 66 percent of consumer respondents who were either very satisfied or satisfied, please see Figure 26. Finally, 93 percent of NF respondents who changed health plans were either very satisfied or satisfied with how case managers considered the cultural needs of consumers compared to 82 percent of HCBS respondents who were either very satisfied or satisfied in this area, please see Figure 27.

Figure 25

Case Manager Considers Cultural Needs By Those Who Changed and Those Who Did Not Change Health Plans

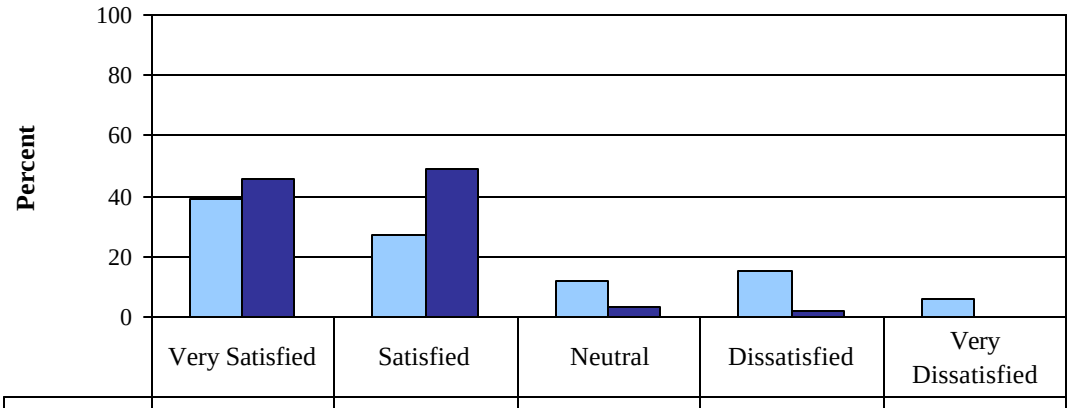


	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	43.5	41.3	6.5	6.5	2.2
Did Not Change Health Plans	50.7	43.0	1.0	4.6	0.7

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-value = 0.015).

Figure 26

Those Who Changed Health Plans, Case Manager Considers Cultural Needs of Consumer, By Respondent

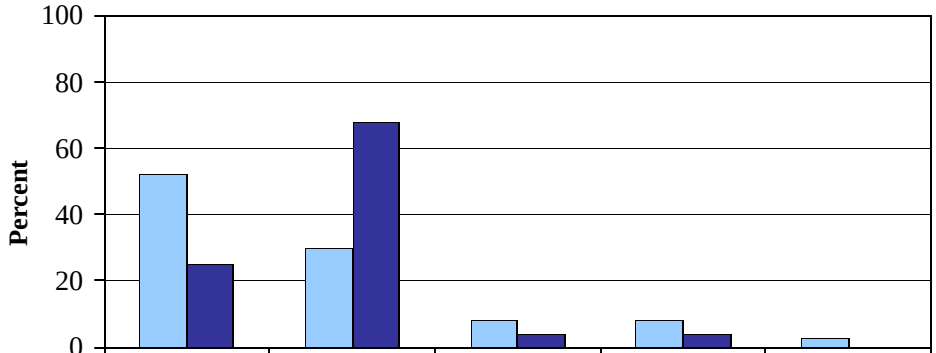


	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Consumer	39	27	12	15	6
Proxy	46	49	3	2	0

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-value = 0.006).

Figure 27

Those Who Changed Health Plans, Case Manager Considers Cultural Needs of Consumer, By Placement



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
HCBS	52	30	8	8	3
NF	25	68	4	4	0

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-value = 0.017).

B. Satisfaction With Doctor

Knowing Ones' Doctor

Overall, 75 percent of all respondents knew their doctors. Seventy-eight (78) percent of respondents who changed health plans knew their doctors, while 75 percent of those who did not change health plans knew their doctors.

For respondents who changed health plans, a statistical difference was found between placement and knowing ones' doctor. HCBS respondents were more likely to know their doctors (84 percent) than were NF respondents (70 percent). No statistical differences were found between age groups, and respondents for those who changed health plans and were satisfied with their doctors.

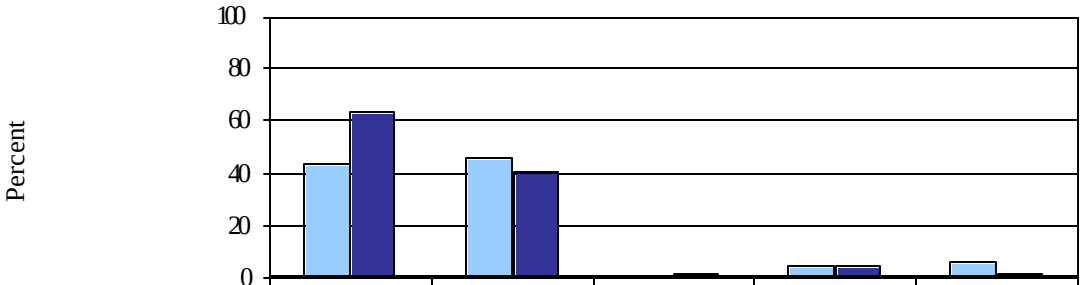
Overall Satisfaction With Ones' Doctor

Overall, 91 percent of all respondents reported being very satisfied to satisfied with their doctors. Eighty-nine (89) percent of respondents who changed health plans were satisfied with their doctors, while 91 percent of respondents who did not change health plans were satisfied with their doctors, please see Figure 28.

There were no statistical differences found between age groups, consumer and proxy respondents, and current placement for those who changed health plans and were satisfied with their doctors.

Figure 28

Overall Satisfaction with Doctor
By Those Who Changed and Those Who Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	43.0	46.1	0.0	4.7	6.2
Did Not Change Health Plans	63.0	40.8	1.8	4.8	2.3

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

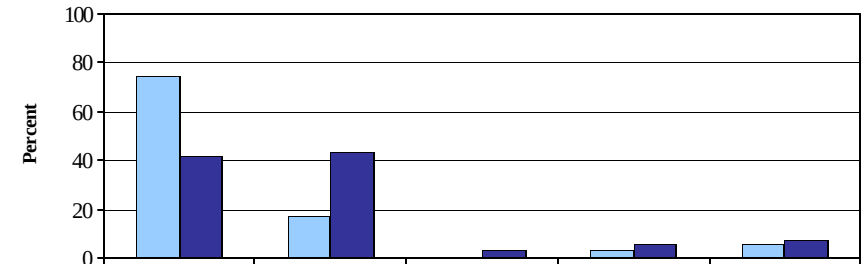
Listening Skills

Overall, 87 percent of all respondents reported being very satisfied to satisfied with how well their doctors listen. Eighty-seven (87) percent of respondents who changed health plans and 87 percent of respondents who did not change health plans reported being very satisfied to satisfied with how well their doctors listen.

A statistical difference was found between respondents for those who changed health plans and their satisfaction with doctors' listening skills. Consumer respondents were more satisfied that their doctor listened to them (91 percent) than were proxy respondents (85 percent), please see Figure 29.

Figure 29

Those Who Changed Health Plans, Doctor Listens to Consumers, by Respondent



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Consumer	74	17	0	3	6
Proxy	42	43	3	6	7

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

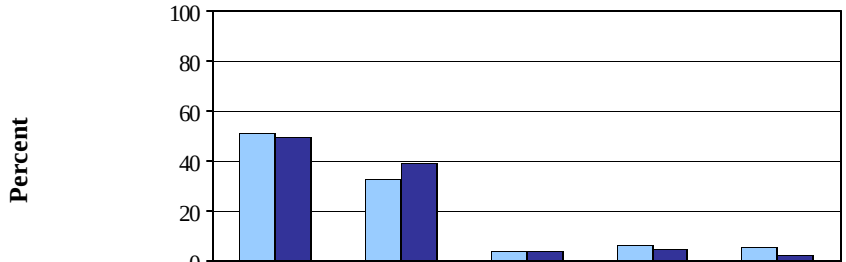
Respect

Overall, 88 percent of respondents reported being very satisfied to satisfied that their doctors respect them. Eighty-three (83) percent of respondents who changed health plans and 89 percent of respondents who did not change health plans reported being very satisfied to satisfied that their doctors respect them, please see Figure 30.

A statistical difference was found between those respondents who changed health plans and placement regarding satisfaction with their doctors showing respect for them. HCBS respondents were more satisfied that their doctors respect them (86 percent) than were NF respondents (79 percent), please see Figure 31.

Figure 30

AHCCCS Doctor Shows Respect, By Those Who Changed and Those Who Did Not Change Health Plans

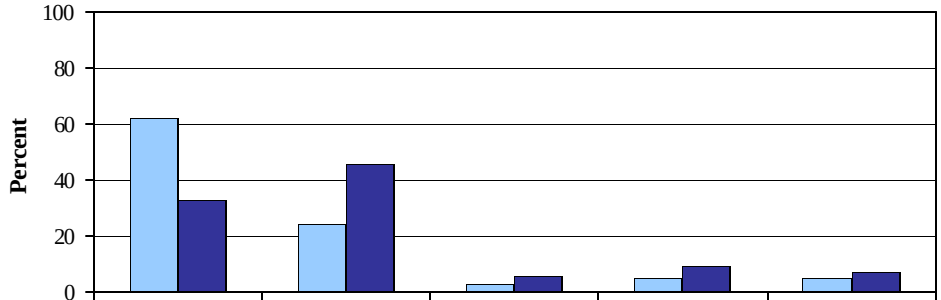


	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	50.8	32.5	4.2	6.7	5.8
Did Not Change Health Plans	49.9	39.1	4.2	4.4	2.3

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

Figure 31

Those Who Changed Health Plans,
Doctor Respects Consumer By Placement



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
HCBS	62	24	3	5	5
NF	33	46	6	9	7

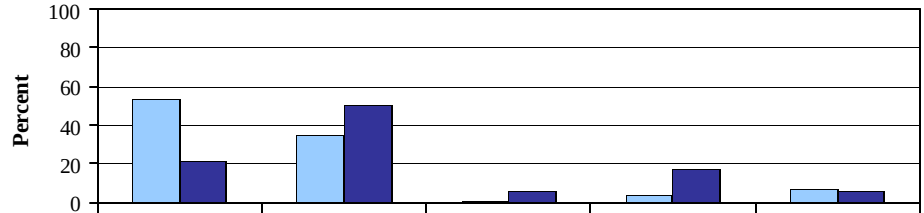
Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-value = 0.035).

Involving Consumers

Overall, 85 percent of respondents reported being satisfied with doctors involving consumers. Eighty-one percent of respondents who changed health plans reported being satisfied, while 87 percent of respondents who did not change health plans reported being satisfied with doctors involving consumers.

Among those respondents who changed health plans, a statistical difference regarding satisfaction with doctors involving consumers was found based on placement. In terms of doctors involving consumers, respondents in the home were significantly more satisfied (88 percent) than were those respondents in nursing facilities (71 percent), see Figure 32.

Figure 32
Those Who Changed Health Plans,
Doctor Involves Consumer By Placement



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
HCBS	53	35	1	4	7
NF	21	50	6	17	6

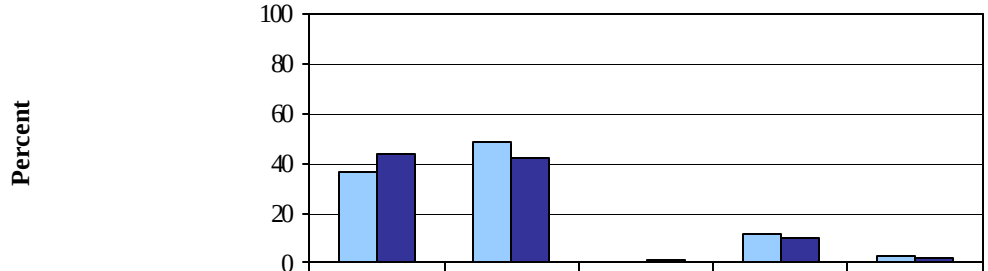
Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-value = 0.053).

Doctor Provides Help When Needed

Overall, 84 percent of respondents reported being satisfied with doctors giving help when needed. Eighty-five (85) percent of respondents who changed health plans reported being satisfied, while 86 percent of respondents who did not changed health plans reported being satisfied with doctors giving help when needed, please see Figure 33.

A statistical difference regarding satisfaction with doctors giving help to consumers when needed was found between the placement of those respondents who changed health plans. Respondents in the home were significantly more satisfied (89 percent) than those respondents in nursing facilities (77 percent) with doctors giving help to consumers when needed, please see Figure 34.

Figure 33
AHCCCS Doctor Provides Help
By Those Who Changed and Those Who Did Not Change Health Plans

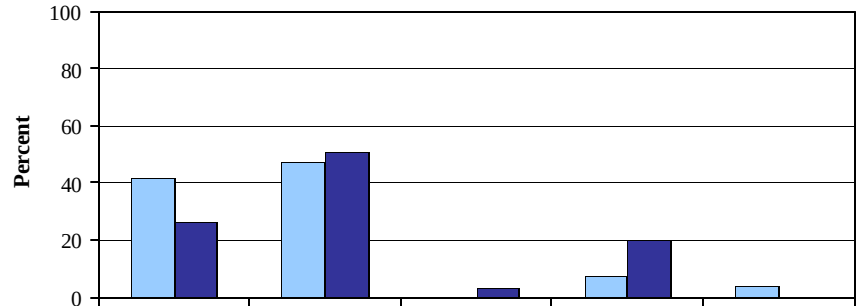


	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	36.7	48.6	0.0	11.9	2.8
Did Not Change Health Plans	43.8	42.4	1.1	10.4	2.2

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-value = 0.053).

Figure 34

Those Who Changed Health Plans,
Doctor Provides Help to Consumer By Placement



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
HCBS	42	47	0	7	4
NF	26	51	3	20	0

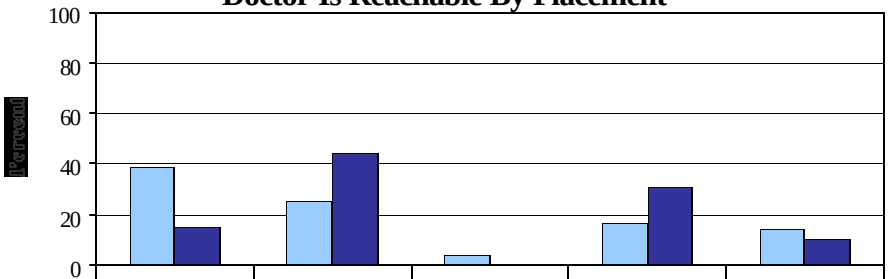
Easy to Reach

Overall, 55 percent of respondents reported that their doctor was easy to reach. Fifty-four (54) percent of those who changed health plans and 55 percent of those who did not change health plans found it easy to reach their doctor.

For those respondents who changed health plans, based on placement there was a statistical difference regarding ease in reaching doctors. Respondents in the home were more satisfied with their ability to reach their doctors (64 percent) than were respondents in nursing facilities (59 percent), please see Figure 35.

Figure 35

Those Who Changed Health Plans,
Doctor Is Reachable By Placement



	Very Easy	Easy	Neutral	Hard	Very Hard
HCBS	39	25	4	17	14
NF	15	44	0	31	10

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p-value = 0.001).

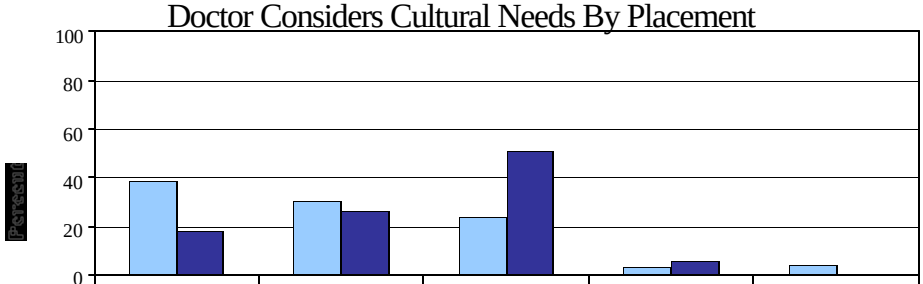
Cultural Needs

Overall, 63 percent of all respondents were very satisfied or satisfied with their doctors' consideration of the individual's cultural background. Sixty-four (64) percent of respondents who changed health plans were satisfied with their doctors' consideration of cultural backgrounds, compared to 58 percent of respondents who did not change health plans.

Among those respondents who changed health plans a statistical difference between the respondents' placement was found regarding the doctors' consideration of cultural background. Respondents in the home were significantly more satisfied with their doctors' consideration of their cultural background (69 percent) than were those respondents in nursing facilities (44 percent), see Figure 36.

Figure 36

Those Who Changed Health Plans,
Doctor Considers Cultural Needs By Placement



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
HCBS	39	30	24	3	4
NF	18	26	51	6	0

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.
Results are statistically different (p-value = 0.008).

C. Satisfaction With HCBS Caregiver

ALTCS consumers who live in a home environment may receive a variety of services, based on their long term care needs. Several members of the health care team, such as attendants (usually daily care for several hours a day), personal care, nurses, and housekeepers (usually weekly or bi-weekly care) provide these home-based services. In order to respond to questions about HCBS caregivers, survey respondents were first asked to identify which service was most important to them. Respondents were read a list of services available to HCBS consumers and asked that they indicate which service was the most important service to the consumer. As you review the responses below, keep in mind that the respondent was answering questions based on which service they indicated was the most important one they received. Also of special note, 27 percent (n=79) of proxies acted as paid caregivers. These proxies were excluded from questions in which they would evaluate themselves.

Ranking of HCBS Services

Overall, respondents ranked attendant care (30 percent) as their most important service, followed by proxy as caregiver (27 percent), personal care (13 percent) housekeeping (10 percent), aide (8 percent), nursing care (6 percent), and meal delivery person (5 percent), see Figure 37. Those who changed health plans (23 percent) and those who did not change health plans (32 percent) also ranked attendant as their most important service, (Figure 38).

For respondents who changed health plans there were significant differences found between age grouping and respondents in the ranking of most important service for HCBS consumers. Respondents who were aged 18-64 ranked attendant as their most important service (31 percent), while respondents who were aged 65+ ranked attendant care as their most important service (29 percent), Figure 39. Consumer respondents who changed health plans ranked attendant as their most important service (31 percent), while proxy respondents ranked proxy as caregiver as their most important service (54 percent), (Figure 40).

Figure 37
Overall, Most Important Services for HCBS Consumers

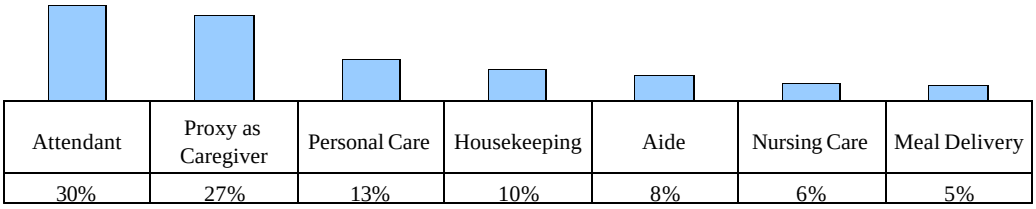
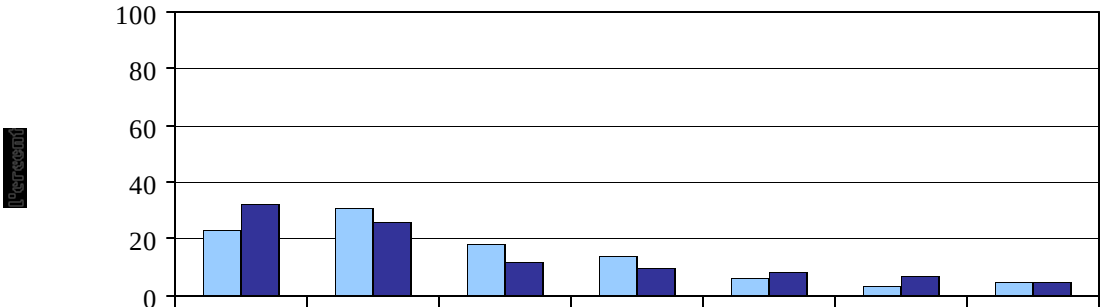


Figure 38

Most Important Services for HCBS Consumers, By Those Who Changed and Those Who Did Not Change Health Plans

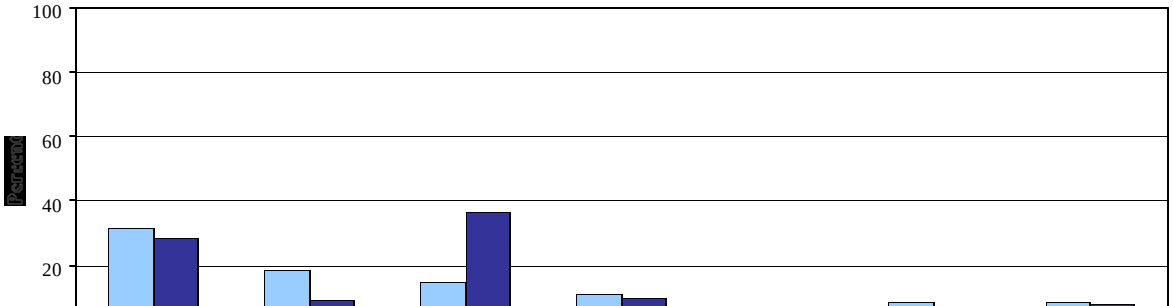


	Attendant Care	Proxy as Caregiver	Personal Care Aide	Housekeeping	Aide	Nursing Care	Meal Delivery
Changed Health Plans	23.1	30.8	18.5	13.8	6.2	3.1	4.6
Did Not Change Health Plans	32.1	26.1	11.9	9.6	8.3	6.9	5

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

Figure 39

Most Important Services For HCBS Consumers, by Age Grouping

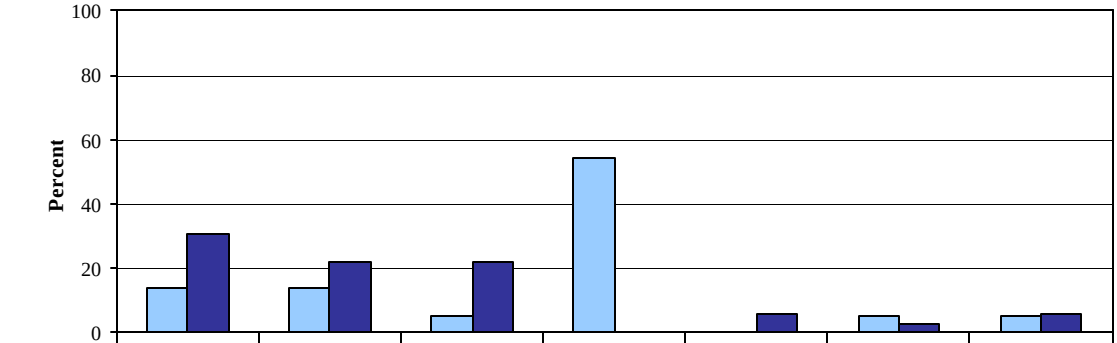


	Attendant Care	Personal Care Aide	Proxy as Caregiver	Housekeeping	Meal Delivery Person	Nursing Care	Aide
18-64	31.3	18.8	14.8	10.9	7.0	8.6	8.6
65+	28.8	9.2	36.8	9.8	3.1	4.3	8

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different ($p = 0.049$).

Figure 40

Most Important Services For HCBS Consumers, by Respondent



	Attendant Care	Personal Care Aide	Housekeeping	Proxy as Caregiver	Nursing Care	Meal Delivery Person	Aide
Proxy	14	14	5	54	0	5	5
Consumer	31	22	22	0	6	3	6

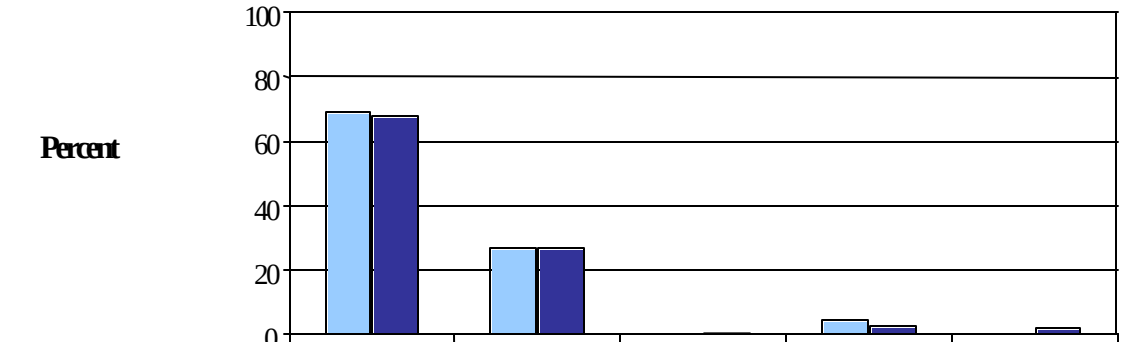
Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p = 0.000).

Satisfaction with Caregiver in HCBS Environment – Overall

Overall, 95 percent of respondents reported being very satisfied to satisfied with their HCBS caregiver. Ninety-six (96) percent of respondents who changed health plans and 95 percent of respondents who did not change health plans reported being very satisfied to satisfied with their HCBS caregiver, please see Figure 41.

There were no statistical differences for those who changed health plans on age grouping or respondent for respondents who were satisfied with their HCBS caregiver.

Figure 41
Overall Satisfaction with HCBS Caregiver
By Those Who Changed and Those Who Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	68.9	26.7	0.0	4.4	0.0
Did Not Change Health Plans	68.1	26.9	0.6	2.5	1.9

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

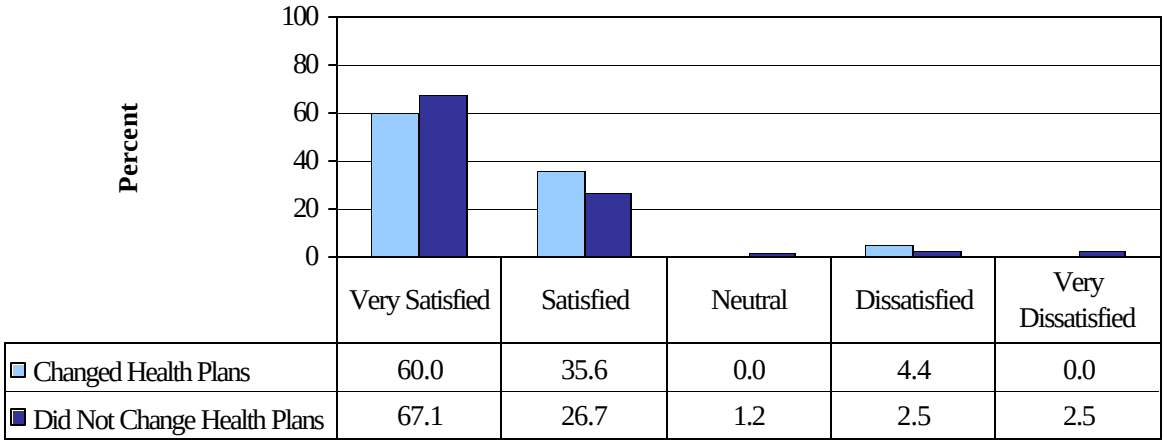
Listening Skills

Overall, 94 percent of all respondents reported being very satisfied to satisfied that HCBS caregivers listen to consumers. Ninety-six (96) percent of respondents who changed health plans and 94 percent of respondents who did not change health plans reported being very satisfied to satisfied that HCBS caregivers listen to consumers, see Figure 42.

There were no statistical differences for those who changed health plans on age grouping or respondent for respondents who were satisfied that HCBS caregivers listen to consumers.

Figure 42

HCBS Caregiver Listens, By Those Who Changed and Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	60.0	35.6	0.0	4.4	0.0
Did Not Change Health Plans	67.1	26.7	1.2	2.5	2.5

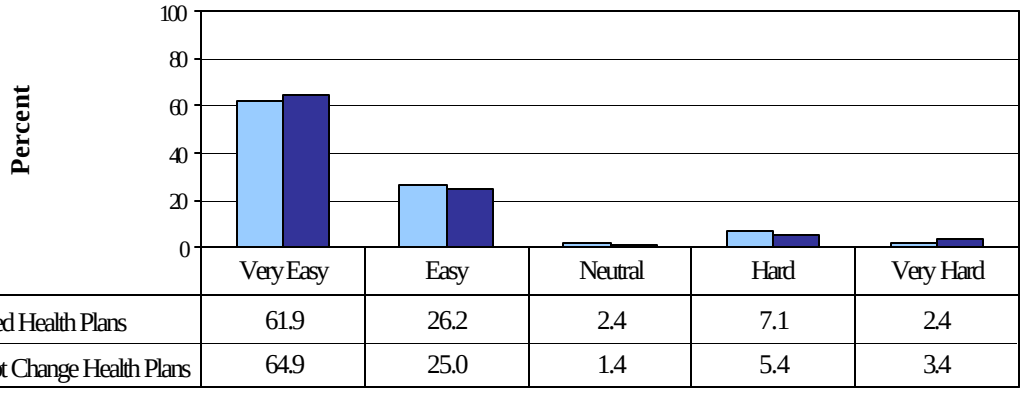
Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

Reaching HCBS Caregiver

Overall, a majority of respondents (91 percent) reported that their HCBS caregiver was easy to reach. Eighty-eight (88) percent of respondents who changed health plans and 90 percent of respondents who did not change health plans reported that their HCBS caregiver was easy to reach, please see Figure 43.

There were no statistical differences for those who changed health plans on age grouping and respondent that HCBS caregivers are easy to reach.

Figure 43
HCBS Caregiver is Reachable
By Those Who Changed and Those Who Did Not Change Health Plans



	Very Easy	Easy	Neutral	Hard	Very Hard
Changed Health Plans	61.9	26.2	2.4	7.1	2.4
Did Not Change Health Plans	64.9	25.0	1.4	5.4	3.4

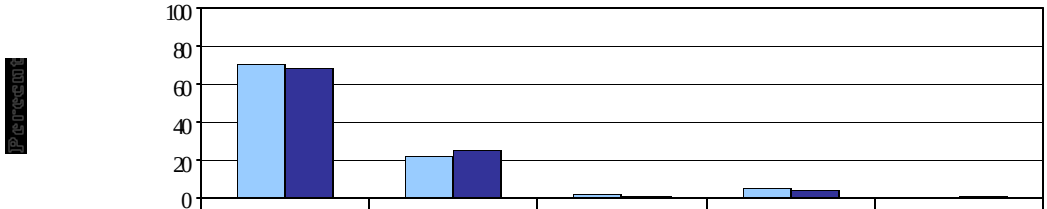
Provides Help

Overall, 90 percent of all respondents reported that they were very satisfied or satisfied that they get the help they need from HCBS caregivers. Ninety-three (93) percent of respondents who changed health plans and 94 percent of respondents who did not change health plans reported that they were very satisfied or satisfied that they get the help they need from HCBS caregivers, please see Figure 44.

There were no statistical differences for those who changed health plans on age grouping and respondent for this question.

Figure 44

HCBS Caregiver Provide Help,
By Those Who Changed and Those Who Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	70.7	22.0	2.4	4.9	0.0
Did Not Change Health Plans	68.8	24.8	1.4	4.3	0.7

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

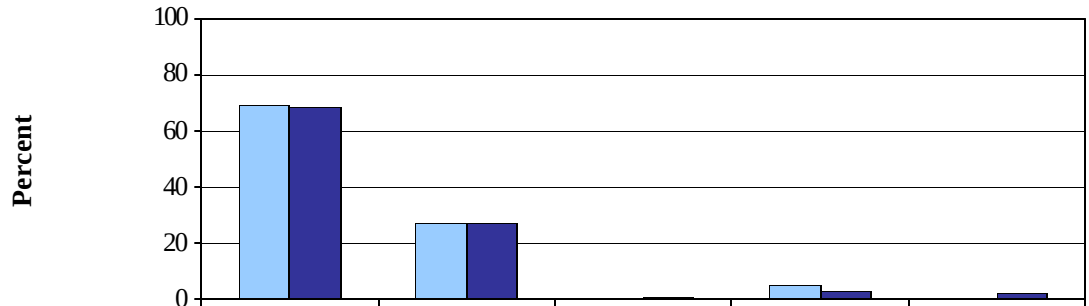
Respecting Consumers

Overall, 95 percent of all respondents reported that they were very satisfied to satisfied that HCBS caregivers respect consumers. Ninety-six (96) percent of respondents who changed health plans and 95 percent of respondents who did not change health plans reported that they were very satisfied to satisfied that HCBS caregivers respect consumers, please see Figure 45.

There were no statistical differences for those who changed health plans on age grouping and respondent for this question.

Figure 45

HCBS Caregiver Shows Respect
By Those Who Changed and Those Who Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	68.9	26.7	0.0	4.4	0.0
Did Not Change Health Plans	68.1	26.9	0.6	2.5	1.9

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

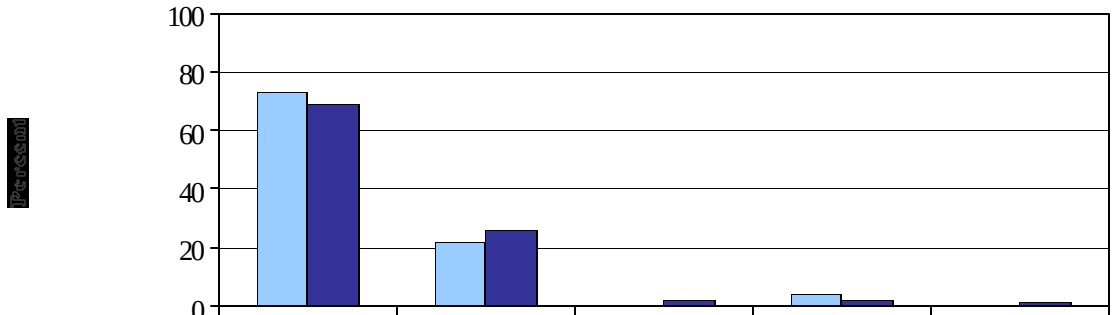
Involving Consumers

Overall, 95 percent of respondents reported that they were very satisfied to satisfied with HCBS caregivers involving consumers. One-hundred (100) percent of respondents who changed health plans and 95 percent of respondents who did not change health plans reported that they were very satisfied to satisfied with HCBS caregivers involving consumers, see Figure 46.

There were no statistical differences for those who changed health plans on age grouping and respondent for this question.

Figure 46

HCBS Caregiver Involves Consumer,
By Those Who Changed and Those Who Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	73.3	22.2	0.0	4.4	0.0
Did Not Change Health Plans	68.9	26.1	1.9	1.9	1.2

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

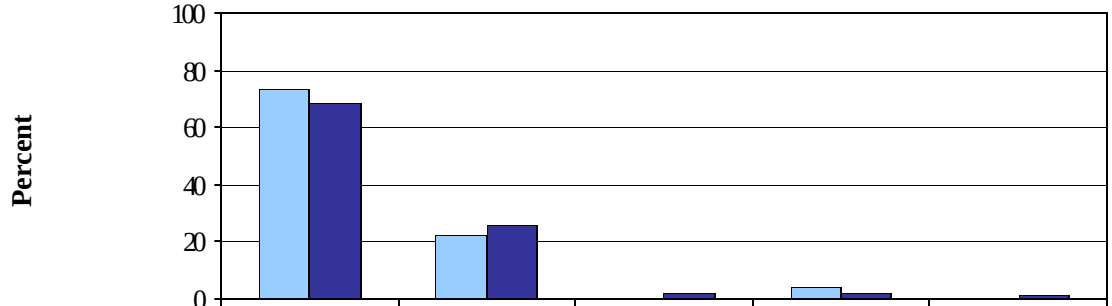
Cultural Needs

Overall, 97 percent of all respondents reported being very satisfied to satisfied with HCBS caregiver's consideration of their cultural needs. Ninety-four (94) percent of respondents who changed health plans and 98 percent of respondents who did not change health plans reported being very satisfied to satisfied with HCBS caregivers' consideration of their cultural needs, see Figure 47.

There were only one significant difference between those who did not change health plans and those who did. Respondents reported that consumers ages 18 through 64 who did not change health plans (98 percent) were more satisfied with the HCBS caregiver's consideration of their cultural needs than consumers in the same age group who changed health plans (89 percent).

Figure 47

HCBS Caregiver Considers Cultural Needs
By Those Who Changed and Those Who Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	73.3	22.2	0.0	4.4	0.0
Did Not Change He4alth Plans	68.9	26.1	1.9	1.9	1.2

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

D. Satisfaction With NF Caregiver

ALTCS consumers living in a nursing care facility may receive a variety of services to meet their long term care needs. As with HCBS consumers, members of the health care team include nurses, aides, social workers, and therapists. In order to respond to questions about nursing facility caregivers, respondents were first asked to determine which one of these services was most important to them. A list of services provided to consumers in a nursing care facility was read to the respondents. From this list, the respondent was asked to indicate which service was the most important service that the consumer received and then respond to satisfaction questions on that one service. Also note, if a proxy was a paid caregiver they were excluded from questions in which they would evaluate themselves.

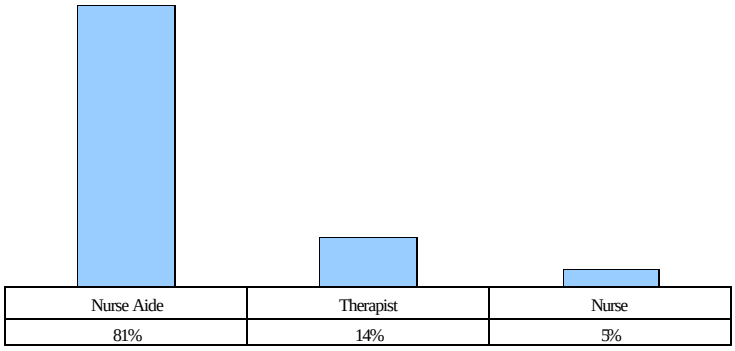
Ranking of NF Services

Overall, respondents ranked nurse's aide (81 percent) as their most important service, followed by therapist (14 percent), and finally nurse (5 percent). Those who changed health plans (81 percent) and those who did not change health plans (83 percent) also ranked nurse's aide as their most important service, please see Figure 48. Although social worker was listed as an option for most important services in the NF setting, no respondent selected this category.

There were no statistical differences found for those who changed health plans on age grouping and respondent for this question.

Figure 48

Most Important Services for NF Consumers



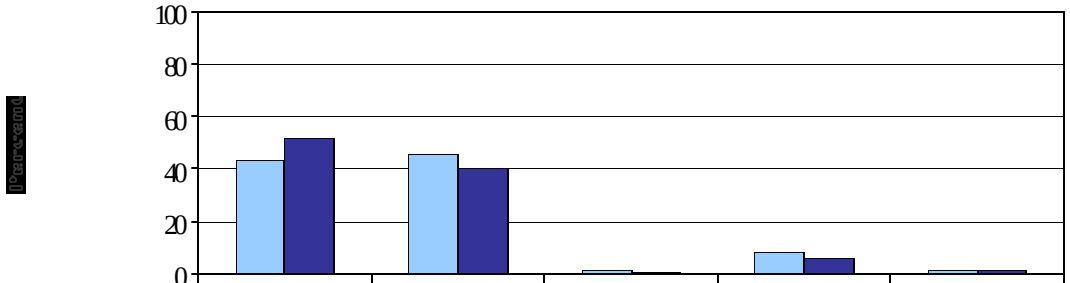
Overall Satisfaction

Overall, 90 percent of all respondents reported being very satisfied to satisfied with their NF caregiver. Eighty-nine (89) percent of respondents who changed health plans and 92 percent of respondents who did not change health plans reported being very satisfied to satisfied with their NF caregiver, please see Figure 49.

There were no statistical differences for those who changed health plans on age grouping or respondent for those who were satisfied with their NF caregiver.

Figure 49

Overall Satisfaction with NF Caregiver
By Those Who Changed and Those Who Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	43.4	45.8	1.2	8.4	1.2
Did Not Change Health Plans	51.9	40	0.9	5.6	1.6

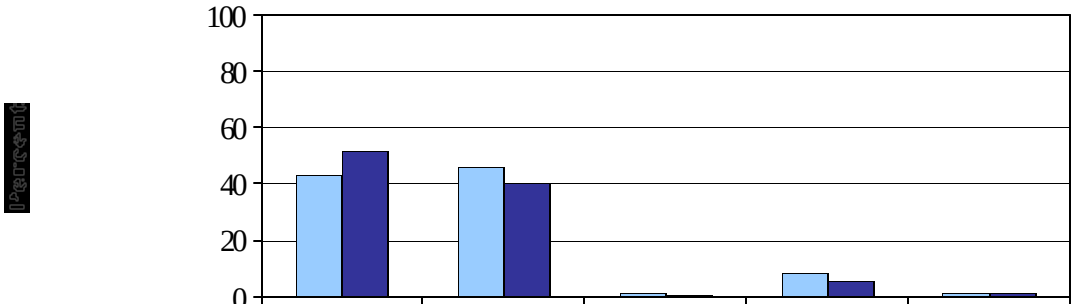
Listening Skills

Overall, 91 percent of all respondents reported being very satisfied to satisfied that the NF caregiver listened to their concerns. Eighty-nine (89) percent of respondents who changed health plans and 92 percent of respondents who did not change health plans reported being very satisfied to satisfied that the NF caregiver listened to their concerns, please see Figure 50.

There were no statistical differences for those who changed health plans on age grouping or respondent on this question.

Figure 50

Satisfaction that NF Caregiver Listens, Comparison Among Consumers Who Changed and Who Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	43.4	45.8	1.2	8.4	1.2
Did Not Change Health Plans	51.9	40.0	0.9	5.6	1.6

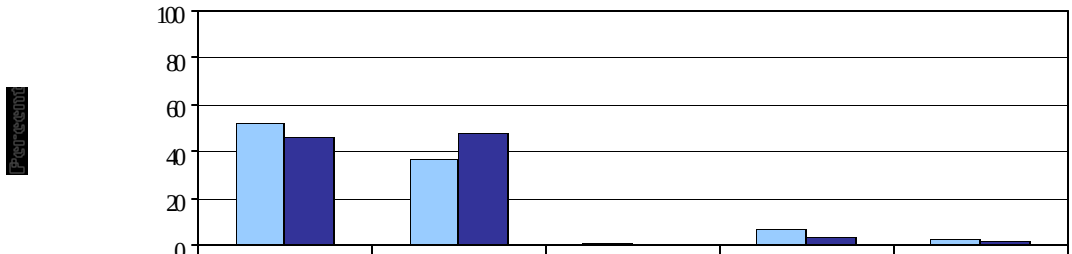
Reaching NF Caregiver

Overall, a majority of respondents (89 percent) reported that their NF caregiver was easy to reach. Eighty-nine (89) percent of respondents who changed health plans and 94 percent of respondents who did not change health plans reported that their NF caregiver was easy to reach, please see Figure 51.

There was a statistical difference among those who changed health plans on respondent grouping. Proxy respondents who changed health plans found it easier to reach their NF caregiver (89 percent) than consumer respondents who tried to reach their NF caregiver (66 percent), please see Figure 52.

Figure 51

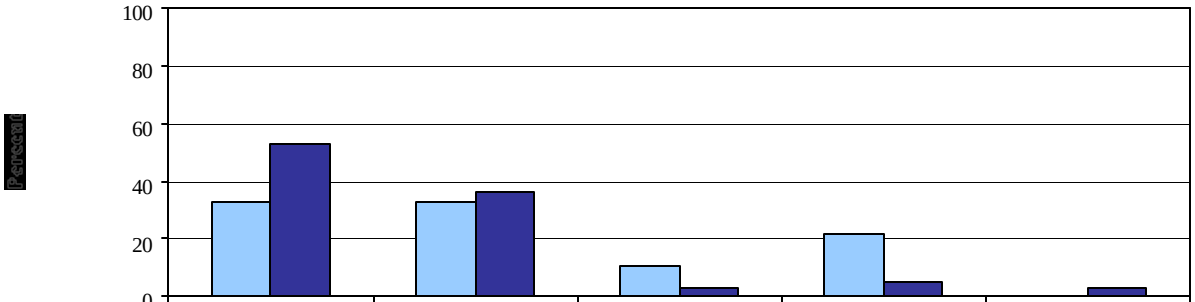
NF Caregiver is Reachable Comparison
By Those Who Changed and Those Who Did Not Change Health Plans



	Very Easy	Easy	Neutral	Hard	Very Hard
Changed Health Plans	52.4	36.6	1.2	7.3	2.4
Did Not Change Health Plans	46.6	47.6	0.6	3.5	1.6

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

Figure 52
Those Who Changed Health Plans, NF Caregiver Easy to Reach
by Respondent



	Very Easy	Easy	Neutral	Hard	Very Hard
Consumer	33	33	11	22	0
Proxy	53	36	3	5	3

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p = 0.027).

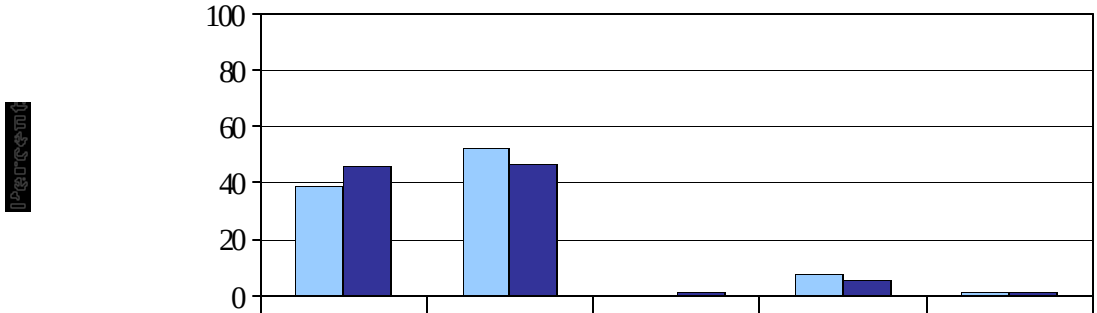
Provides Help

Overall, 92 percent of all respondents reported that they were very satisfied or satisfied that they get the help they need from NF caregivers. Ninety-one (91) percent of respondents who changed health plans and 92 percent of respondents who did not change health plans reported that they were very satisfied or satisfied that they get the help they need from NF caregivers, please see Figure 53.

There was a statistical difference among those who changed health plans on age grouping. One hundred (100) percent of respondents aged 18-64 reported that they were very satisfied or satisfied that they get the help they need from NF caregivers, compared to respondents aged 65+ (89 percent), please see Figure 54.

Figure 53

NF Caregiver Provides Help Needed
By Those Who Changed and Those Who Did Not Change Health Plans

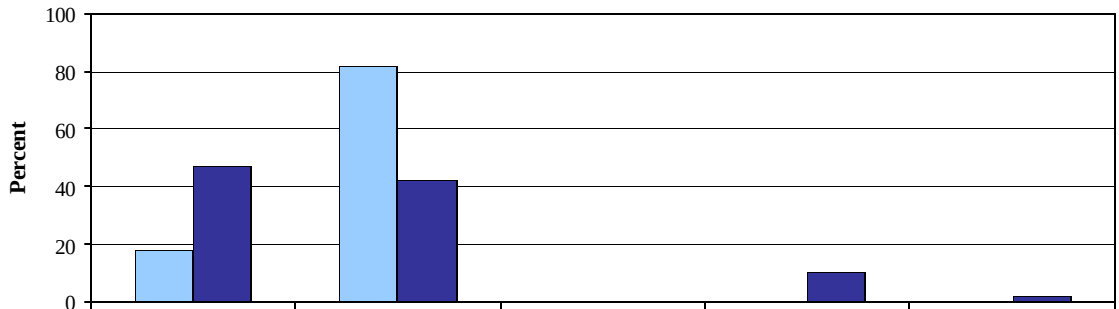


	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	39.0	52.4	0.0	7.3	1.2
Did Not Change Health Plans	45.8	46.4	1.0	5.6	1.3

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

Figure 54

Those Who Changed Health Plans,
NF Caregiver Provides Needed Help by Age Grouping



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
18-64	18	82	0	0	0
65+	47	42	0	10	2

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents. Results are statistically different (p = 0.012).

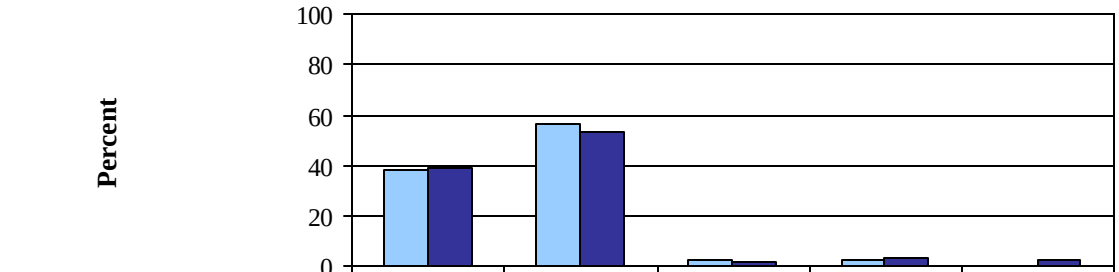
Respecting Consumers

Overall, 95 percent of all respondents reported that they were very satisfied to satisfied that NF caregivers respect consumers. Ninety-eight (98) percent of respondents who changed health plans and 95 percent of respondents who did not change health plans reported satisfaction with NF caregivers respecting consumers, see Figure 55.

There were no statistical differences for those who changed health plans on age grouping and respondent for this question.

Figure 55

NF Caregiver Shows Respect Comparison Among Consumers Who Changed and Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	38.6	56.8	2.3	2.3	0.0
Did Not Change Health Plans	39.7	53.7	1.4	2.8	2.3

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

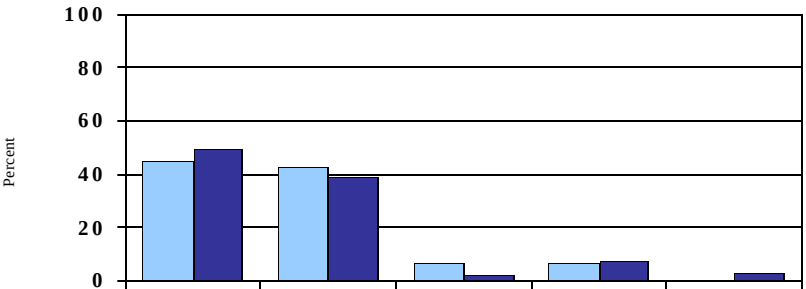
Involving Consumers

Overall, 90 percent of respondents reported that they were very satisfied to satisfied with NF caregivers involving consumers. Eighty-eight (88) percent of respondents who changed health plans and 88 percent of respondents who did not change health plans reported that they were very satisfied to satisfied with NF caregivers involving consumers, please see Figure 56.

There were no statistical differences for those who changed health plans on age grouping and respondent for this question.

Figure 56

NF Caregiver Involves Consumer in Decision Making, Comparison Among Consumers Who Changed and Who Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plan	45.1	42.7	6.1	6.1	0.0
Did Not Change Health Plan	49.7	38.6	1.6	7.5	2.6

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

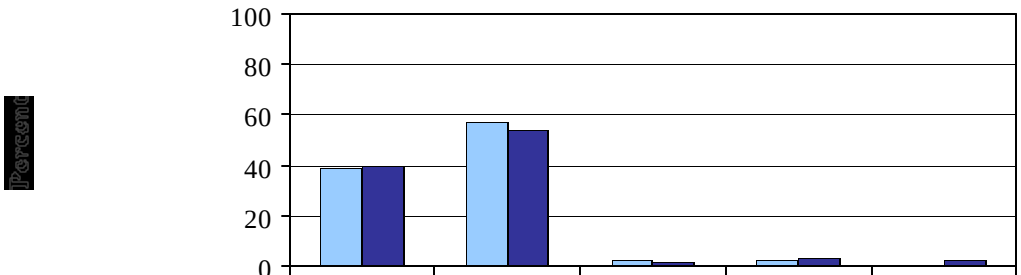
Cultural Needs

Overall, for those respondents who said cultural needs of their NF caregiver was important, 99 percent reported being very satisfied to satisfied with NF caregiver's consideration of their cultural needs. Ninety-five (95) percent of respondents who changed health plans and 94 percent of respondents who did not change health plans reported being very satisfied to satisfied with NF caregivers' consideration of their cultural needs, please see Figure 57.

There were no statistical differences for those who changed health plans on age grouping and respondent with HCBS caregivers' consideration of their cultural needs.

Figure 57

NF Caregiver Considers Cultural Needs, Comparison Among Consumers Who Changed and Who Did Not Change Health Plans



	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
Changed Health Plans	38.6	56.8	2.3	2.3	0.0
Did Not Change Health Plans	39.7	53.7	1.4	2.8	2.3

Notes: Percents may not add to 100 due to rounding. Not all questions were answered by all respondents.

IX. CONCLUSION

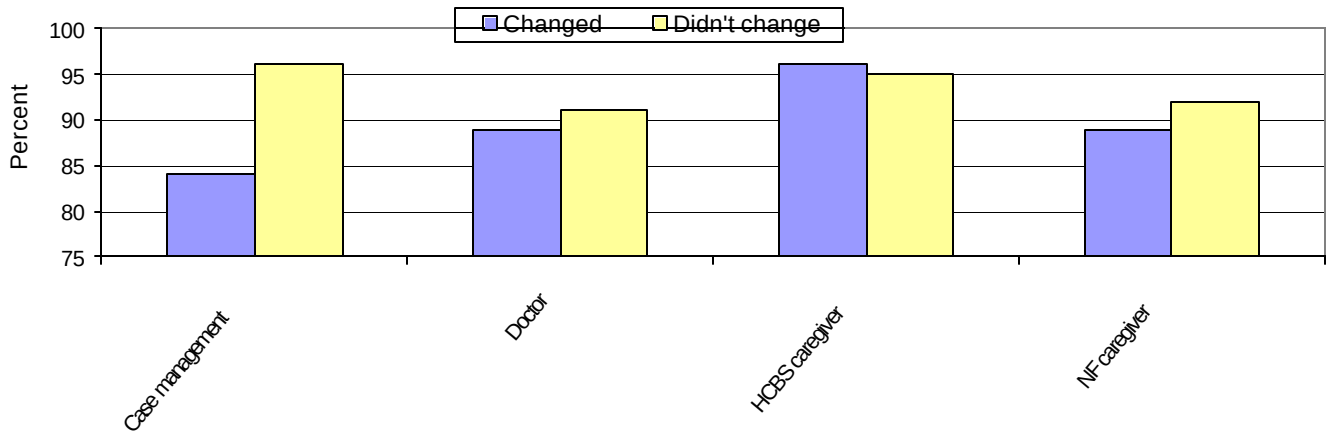
The results of this final phase of research were used to develop policy considerations to guide state leaders and health care professionals as they continue to address long term care in the future.

After choice, how did health plans rate on satisfaction?

Very well. Depending on the health plan serving them, consumers were either very satisfied or satisfied with their plan 91% to 95% of the time. Specifically, consumers had high satisfaction levels with their case managers, doctors and caregivers in either home and community-based settings or nursing facilities. And it was the doctor area that showed the largest satisfaction increase from the years 2000 to 2001 – from 84% to 91%. Only "reachability" of a case manager, doctor or caregiver received a lower rating than in the first survey.

Whether respondents changed plans or not, their satisfaction levels within each of the four measured areas remained high, as show below:

Figure 58
Overall satisfaction between those who changed and did not change plans



Policy considerations :

- Monitor and compare the performance of health plans.
- Monitor which health plans are selected by new ALTCS members.
- Evaluate further the impact choice has on quality; on the rates paid to health plan by AHCCCS; and on providers, their networks and their rates.

Is the actual consumer the only ALTCS customer?

Not at all. Out of 844 respondents in the last phase of this project, 76% were proxy respondents while only 24% were actual consumers enrolled in the ALTCS program. This shows that in addition to the actual consumer, proxies are a valuable source of information because they are so involved with the care of the consumer.

There was little or no difference between the way proxies and consumers answered survey questions in all areas except the case manager area, where proxies showed a higher satisfaction level - 95% vs. 89%.

Policy considerations:

- Recognize that proxies are also key customers in the private and public long term care area.
- Obtain more data and learn how proxies impact care and services provided by long term care.
- Determine whether and how future surveys should be modified for proxy input.

Case managers: How are they viewed?

While it is less likely that consumers will change caregivers when they opt for service from another health plan, case managers are a different story. They do change because they work for a specific plan, unlike caregiver agencies that can contract with all available plans. It is noteworthy, therefore, that consumers and proxies in this research project reported an overall high rate of satisfaction (93%) with their case managers. This area had the most differences between those who changed plans (84% satisfaction) and those who did not change plans (96%).

Policy considerations:

- Health plans should evaluate case management to determine if there is increased improvement in this area among existing consumers over time.
- Continue to review and use best practices to accommodate new consumers when they become enrolled in a health plan.

Choice: What we know, what we don't

This research project answered some questions about choice but left many more unanswered. Across the country, comprehensive data about choice within the long term care arena is thin at best. It is still too new of a concept, particularly among Medicaid programs.

What we know from this project is that despite being offered a choice of three health plans, most consumers chose to remain with their existing plan – Maricopa Long Term Care Plan. We also

know that of those consumers who chose to change health plans, the top four reasons were location of a hospital, quality of a hospital, quality of a doctor's services and location of a doctor.

What we don't know is why choice had such little effect on satisfaction levels, which remained high among those who changed and those who did not change health plans. We also don't know why so many people chose to remain with Maricopa Long Term Care Plan. And we don't know if brand new customers of ALTCS make choices for different reasons from those already in the program.

It is not unusual that this project raised more questions than it answered because research is so new in this area. So is expertise to conduct this kind of research. But this is a starting point to determine where to go next both in research and in planning.

Policy considerations:

- Explore what differences motivate so many consumers to remain or not remain with their existing plan when choice is offered.
- Explore what motivates brand new ALTCS members to choose one plan over another.
- Promote more expertise in this kind of research.

What lessons did we learn to improve for future research?

As consumer involvement in long term care increases, states and health care professionals continue to look for the best ways to survey these consumers and their families. Time and money, of course, will restrict a survey that can address every area of interest among this population. Still, even a survey with limits will turn up valuable lessons for further research, as did this one. Some lessons include:

- Early in the planning, clearly determine the focus of the survey and how the data will be used both from strategic planning and operational efforts.
- If resources are scarce, limit the sample stratification and thus focus more time and analysis in key areas.
- To reduce the cost of the survey, explore ways to efficiently identify those customers who are cognitively impaired and need a proxy to respond in an efficient way.
- Before beginning research work, determine how proxy responses vs. consumer responses will add or detract from the survey, if at all.
- Standardize the way statewide surveys are worded and conducted so there is comparable feedback and the same baselines for further such surveys.

Summary

Long term care consumers in Maricopa County are extremely satisfied with their long term care services, whether they have changed health plans or not.

Proxies have emerged as an important party speaking on behalf of consumers, and will be included as a critical part of future research.

More research is needed to determine how much difference choice makes, why new consumers choose one plan over another and why consumers choose to remain or not remain with their existing plan.

X. LESSONS LEARNED

Beyond the fact that there never is enough time or money to develop, implement and conduct a survey that addresses every area of interest in the long-term population, several valuable lessons were learned by the staff involved with this project. Some of the more broad lessons are:

- Limit focus of survey: We are dealing with a population that frequently requires more time to process questions and may not be so tolerant of a survey requiring more than 15-20 minutes to complete. By addressing fewer areas the overall survey length could have been decreased. This would allow more time for the survey staff to explain questions and allow for members to think through their answers and provide more balanced information. In this way a more in-depth understanding of why members are satisfied could be obtained. It could also enhance satisfaction for all involved by decreasing frustration of feeling rushed, having questions answered with consideration and not just the first thing to get interview over, and a member capable of providing the information referring call to a caregiver.

- Ensure that all aspects are addressed: Frequently individuals have a specialized focus within the various areas of long-term care. It is important to fully explore all aspects of the areas/issues being studied. Only in this way can the complete picture be discovered. For instance, AHCCCS was stressing the need to look at members who changed health plans. To fully evaluate why and how choice is made, we also needed to look at why members chose to stay with their current health plan. Although questions were developed for both aspects, only those for members who changed plans were included in the final tool. The unintended omission of the other questions has limited the analysis and findings regarding choice.

- Limit the sample stratification: Each stratification (i.e. age grouping, placement, gender, etc) increases the size of the population requirements that also increases the resource and time requirements. In addition, the more stratification levels utilized the higher the risk of groupings ending up with a size that is small. The small size in some areas may require alterations in analysis and limits to the level of evaluation available. In some cases changes in sample or the unknown number of members meeting criteria require late adjustments to a study. For example, the number of members who would select a plan other than Maricopa Managed Care Systems was an unknown factor. The number of members interviewed prior to choice who then elected to change plans was small. Adjustments to the sampling methodology needed to be made to ensure the ability to make comparisons.

- Develop system for identifying cognitive abilities of sample members prior to survey: With a large portion of the long-term care population having some cognitive impairment, it is vital to determine to what degree this population could participate in the survey. In today's society individuals tend to address questions to the younger companion, such as a daughter/son or caregiver, rather than the elderly individual. This is true even when the elderly individual is capable of answering for themselves. To prevent the interviewing of proxies when the member could respond, a uniform method should be adopted that will consistently determine when a member is unable to participate in a survey.

- Identify member proxies ahead of time and determine their relationship to member: As stated above, a large portion of the long-term care population has some cognitive impairment. Exclusion of these members, although an option, would eliminate a vital, and often the most vulnerable, portion of the population. Identifying a family member or legal guardian who has frequent involvement with the member was found to be extremely useful. Developing a method for determination of the appropriate "proxy" to contact is vital to any success of this type of survey.

  Caution must be taken to ensure that members are not excluded because they have a physical impairment that makes it harder for them to respond. People unfamiliar with this population often construe physical handicaps as a sign of diminished cognitive abilities. Our elderly and physically handicapped members should never be excluded just because it is harder for us to obtain information directly from them.

- Determine what constitutes a proxy: Before starting a survey where proxies may be interviewed, it is important to determine who will be accepted as the "proxy". This definition can vary depending on the purpose of the survey. For AHCCCS member's any number of individuals could function as a survey proxy from relatives and legal guardians (used in this study) to attendant care givers and nursing facility staff members. Identifying who will be accepted and how they will be identified will speed the survey process when cognitive impairment has been determined and another source of information required.

- Develop method for adjusting to population changes: Long-term care populations traditionally have less fluctuation in enrollment and placement than its acute counterpart. However, changes do occur, especially when a large portion of the sample reside in some type of home and community setting. In addition, this population often has a higher risk of acute hospitalization and death. This issue is more far-reaching in longitudinal studies than one time surveys. In this survey, AHCCCS chose to adjust the population size at the beginning to account for possible placement changes and member deaths. Adjusting the population size may not always be suitable, as it also increases cost and manpower requirements. Therefore, it is vital to evaluate the population under consideration, determine how population changes could affect the results, and develop from the outset a method(s) to deal with any issue that may arise in this area.

ABOUT THE LTC SURVEY

To learn more about how to strategically plan for the future of our long term care systems in Arizona, the Flinn Foundation funded the first state Medicaid long term care consumer satisfaction survey.

ABOUT THE DATA

The quantitative data presented in this report was collected from participants of a consumer telephone survey. Individuals who participated were either direct members of the care (consumers) or making decisions for the consumer about their care (proxies).

ABOUT THE WHAT CONSUMERS SAY BOOK

This series, What Consumers Say Book, is funded by a grant from The Flinn Foundation.

This report is the second in a series of four publications. Other documents available are:

1. Final Report
2. Survey Data Book
3. Trifold – Final Report Summary

For more information, please contact:

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Phoenix, Arizona 85034
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APPENDIX A

QUESTIONNAIRE FILE: p0307.run 28 August 2001

FINAL SURVEY TOOL FOR PHASE III

****

Question 1

I am calling because AHCCCS would like to find out what you think about the services {you get|name gets} from the Arizona Long Term Care System (ALTCS). This is a follow-up to a survey we did last year. We want to learn from you and other AHCCCS members so that we can improve our services. We'd appreciate your time to help us.

{This appears if we're talking to a proxy:}
Do you know enough about {name's} long term care to answer some questions about it?

0. CLIENT/NAME IN CALLBOX
1. PROXY (ENTER FAMILY OR FRIEND)
2. MCLTC EMPLOYEE; NO FAMILY PROXY AVAILABLE (exit) (skip to q 998c)

****

Question 1a

This interview will last between 15 to 20 minutes depending upon your answers. Before we begin, we want you to know that your participation is voluntary and your answers are confidential.

No information is ever released that would allow anyone, including AHCCCS or your health care provider, to identify you or anyone else in your family. If you decide you don't want to answer any questions, it will not affect } {your|name's} AHCCCS services or benefits in any way. We would really like your opinion because you and other members know first hand how the program is working. This call may be monitored for quality purposes.

****

{Hidden question}
{Program checks Q1. If interviewing proxy, and gender of ALTCS client not obvious, ask Q1c. This allows use of proper pronoun in following questions. If interviewing client, skip to Q5)

****

Question 1c

GENDER OF ALTCS CLIENT?

IF YOU CAN'T TELL ASK: And is {name} male or female?

1. MALE
2. FEMALE

****

Question 5

First, we would like to ask you about {your own|name's} health.

In general, would you say {your|his|her} health is excellent, very good, good, fair or poor?

1. EXCELLENT
2. VERY GOOD
3. GOOD
4. FAIR
5. POOR

9. REF

****

Question 6

Compared to one year ago, how would you rate {your|name's} health in general now?

Would you say {your|name's} health is much better now than one year ago, somewhat better now than one year ago, about the same as one year ago, somewhat worse now than one year ago, or much worse now than one year ago?

1. MUCH BETTER
2. SOMEWHAT BETTER
3. ABOUT THE SAME
4. SOMEWHAT WORSE
5. MUCH WORSE

9. REF

****

Question 9

{Are you|Is name} currently living at home; in a facility such as Assisted Living or Adult Foster Care; or in a Nursing Home?

1. YES, HOME
2. YES, ASSISTED LIVING
3. YES, ADULT FOSTER CARE
4. YES, NURSING HOME

9. DK/REF

****

Question 9a

Did {you|name} change health plans last fall?

1. YES
2. NO (skip to Q 10)

9. DK/REF (skip to Q 10)

****

Question 9b

{If talking to client:} Did you make the decision to change health plans on your own, or did someone else help you make this decision?

{If talking to proxy:) Was {client's name} able to help you make the decision to change plans, or did you make it on your own?

1. MADE ALONE
2. HAD HELP

9. DK/REF

****

Question 9c

Why did {you|name} change health plans?

[DO NOT READ LIST]

1. Recognized plan name
2. Bad experience w/ previous plan
3. Wanted to keep same Doctor
4. Wanted to keep same case manager
5. Wanted to keep same caregiver
6. Customer service
7. Quality of doctor services
8. Quality of hospital
9. Location of doctor's office
10. Location of hospital
11. Because of other long-term care services
12. Other reason not listed above; [Type 12/"reason"]

[Enter the number for the first reason they name, then prompt for more]
[Separate numbers with a / -- like 2/4/6 or 5/2/12/less expensive]

****

****

Question 9p

And how satisfied {are you|is name} with {your|name's} new health plan compared to {your|name's} old health plan. Would you say {you are|name is} more satisfied, less satisfied, or about the same.

1. MORE SATISFIED
2. LESS SATISFIED
3. ABOUT THE SAME (skip to Q 10)

9. DK/REF (skip to Q 10)

****

Question 9q

Why {are you|is name} {more|less} satisfied with {your|name's} new health plan?
[RECORD VERBATIM]

****

Question 10

The next questions ask about the services provided to {you|name} by {your|his|her} case manager and how satisfied you are with these services.

Do you know who {your|name's} case manager is?

[CLARIFICATION: The case manager is the person who reviews your needs and assists with arranging for services such as Home Delivered Meals, Nursing Services, Housekeeping, Attendant Care, Adult Foster Care, Assisted Living, and Nursing Home Care.]

1. YES
2. NO (skip to Q 50)

9. DK/REF (skip to q 50)

****

Question 11

Is this the same case manager {you had|name had} the last time we spoke with you?

[THAT IS, SINCE LAST OCTOBER]

[ITNERVIEWER: IF 'R' WAS NOT IN PREVIOUS STUDY, ENTER '9']

1. YES
2. NO

9. DK/REF

****

Question 12

How satisfied are you that the case manager listens to you?

Are you very satisfied, satisfied, dissatisfied or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 20

How satisfied are you that the case manager involves you when making decisions about {your|his|her} care?

Would you say very satisfied, satisfied, dissatisfied, very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 21

Have you tried to reach {your|name's} case manager in the last 12 months?

1. YES
2. N0 (skip to Q 26a)

9. DK/REF (skip to Q 26a)

****

Question 25

How easy is it for you to reach {your|name's} case manager?

Would you say it is very easy, easy, hard, or very hard?

1. VERY EASY
2. EASY
3. HARD
4. VERY HARD

8. NEUTRAL/NEITHER
9. DK/REF

****

Question 26

When you call {your|name's} case manager, how satisfied are you that {you get}|he gets|she gets} the help {you need}|he needs|she needs}?

Are you very satisfied, satisfied, dissatisfied or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 26a

DO NOT READ

INTERVIEWER: THIS IS THE PLACE TO QUIT OR START OVER WITH PROXY, IF RESPONDENT HAD DIFFICULTIES UNDERSTANDING AND ANSWERING PRIOR QUESTIONS

1. CONTINUE, R IS DOING OK, OR PROXY CAN GO ON FROM HERE
2. QUIT, R NOT ABLE TO GIVE ACCURATE ANSWERS & NO PROXY (skip to Q 260)
3. PROXY COMES TO PHONE-START OVER AT Q1 (skip to Q 1)

****

Question 27

How satisfied are you with the respect {your|name's} case manager shows you?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 30

If {you|name} needed some other service that {you are not|he is not|she is not} currently receiving to maintain independence, what would it be?

[CLARIFICATION on "INDEPENDENCE:" Doing more on your own.]

****

Question 40

Research indicates that some health care providers may be more sensitive to the cultural needs of their patients than others. Cultural needs refer to beliefs you were raised with, your family heritage, your religion, the foods you enjoy, and your lifestyle.

How satisfied are you that {your|name's} case manager takes into consideration {your|his|her} special cultural needs? Would you say you are: very satisfied, satisfied, dissatisfied, very dissatisfied or does this not apply to you?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED
5. DOES NOT APPLY

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 41

Overall, how satisfied are you with the case manager now?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED (skip to Q 46)
4. VERY DISSATISFIED (skip to Q 46)

8. NEITHER/NEUTRAL (skip to Q 50)
9. DK/REF (skip to Q 50)

****

Question 42

What is the main reason you are satisfied with the case manager?

Is it because he or she listens to you, involves you in planning services, treats you with respect, is your advocate when necessary, is accessible, helps you retain your independence, considers race, beliefs and customs, or the quality of services received is good?

1. LISTENS (skip to Q 50)
2. INVOLVES IN PLANNING (skip to Q 50)
3. RESPECTS YOU (skip to Q 50)
4. ADVOCATE (skip to Q 50)
5. ACCESSIBLE (skip to Q 50)
6. RETAIN INDEPENDENCE (skip to Q 50)

7. CONSIDERS CULTURE (skip to Q 50)
8. GOOD SERVICES (skip to Q 50)
9. DK/REF (skip to Q 50)

****

Question 46

What is the main reason you are dissatisfied with your case manager?

Is it because he or she doesn't listen to you, doesn't involve you in planning services, does not treat you with respect, is not your advocate when necessary, is not accessible, does not help you retain your independence, doesn't consider race, beliefs and customs, or the quality of services received is not good?

1. DOES NOT LISTEN
2. DOES NOT INVOLVE IN PLANNING
3. DOES NOT RESPECT YOU
4. DOES NOT ADVOCATE
5. ISN'T ACCESSIBLE
6. DOES NOT RETAIN INDEPENDENCE

7. DOES NOT CONSIDER CULTURE
8. BAD SERVICES
9. DK/REF

****

Question 50

The next questions ask about the services provided to {you|name} by {your|his|her} doctor.

We are interested in knowing how satisfied you are with the care provided by {your|name's} doctor.

Do you have one person you think of as {your|name's} doctor?

1. YES
2. NO (skip to Q 80)

9. DK/REF (skip to Q 80)

****

Question 51

Is this the same doctor {you had|name had} since we spoke with you last? [SINCE LAST OCTOBER]

[INTERVIEWER: IF 'R' WAS NOT IN PREVIOUS STUDY, ENTER '9']

1. YES
2. NO

9. DK/REF

****

Question 55

How satisfied are you that the doctor listens to you?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 60

How satisfied are you that {your|name's} doctor involves you when making decisions about {your|his||her} care?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 67

When you call {your|name's} doctor, how easy is it for you to reach someone who can help you?

Would you say it is very easy, easy, hard, or very hard?

[CLARIFICATION: Anyone who can answer your questions]

1. VERY EASY
2. EASY
3. HARD
4. VERY HARD
5. DOESN'T APPLY TO RESPONDENT (skip to Q 70)

8. NEUTRAL/NEITHER
9. DK/REF

****

Question 68

When you call {your|name's} doctor, how satisfied are you that {you get|he gets|she gets} the help {you need|he needs|she needs}?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED
5. DOESN'T APPLY TO RESPONDENT

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 70

How satisfied are you with the respect shown by {your|name's} doctor for what you have to say?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 72

How satisfied are you that {your|name's} doctor takes into consideration {your|his|her} special cultural needs? Would you say you are: very satisfied, satisfied, dissatisfied, very dissatisfied or does this not apply to you?

[Cultural needs refer to beliefs you were raised with, your family heritage, your religion, the foods you enjoy, and your lifestyle.]

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED
5. DOES NOT APPLY

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 73

Overall, how satisfied are you with {your|name's} doctor now?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED (skip to Q 75)
4. VERY DISSATISFIED (skip to Q 75)

8. NEITHER/NEUTRAL (skip to Q 77)
9. DK/REF (skip to Q 77)

****

Question 74

What is the main reason you are satisfied with {your|name's} doctor?

Is it because he or she listens to you, involves you in planning services, treats you with respect, is your advocate when necessary, is accessible, helps you retain your independence, considers race, beliefs and custom, or the quality of services received is good?

1. LISTENS (skip to Q 77)
2. INVOLVES IN PLANNING (skip to Q 77)
3. RESPECTS YOU (skip to Q 77)
4. ADVOCATE (skip to Q 77)
5. ACCESSIBLE (skip to Q 77)
6. RETAIN INDEPENDENCE (skip to Q 77)

7. CONSIDERS CULTURE (skip to Q 77)
8. GOOD SERVICES (skip to Q 77)
9. DK/REF (skip to Q 77)

****

Question 75

What is the main reason you are dissatisfied with your doctor?

Is it because he or she doesn't listen to you, doesn't involve you in planning services, does not treat you with respect, is not your advocate when necessary, is not accessible, does not help you retain your independence, doesn't consider race, beliefs and custom, or the quality of services received is not good?

1. DOES NOT LISTEN
2. DOES NOT INVOLVE IN PLANNING
3. DOES NOT RESPECT YOU
4. DOES NOT ADVOCATE
5. ISN'T ACCESSIBLE
6. DOES NOT RETAIN INDEPENDENCE

7. DOES NOT CONSIDER CULTURE
8. BAD SERVICES
9. DK/REF

****

Question 77

We know there are many different types of insurance plans that pay for doctor visits.

Does AHCCCS pay for {your|name's} doctor visits?

[IVWR: MAY KNOW AS: Maricopa Long Term Care, Lifemark, Mercy Care ALTCS]

1. YES (skip to Q 80)
2. NO

9. DK/REF (skip to Q 80)

****

Question 79

Why did you choose that doctor rather than a doctor with Maricopa Long Term Care, Lifemark, Mercy Care, AHCCCS, ALTCS or LTC?

{Verbatim answer recorded}

****

Question 80
{Hidden question}
{Program checks answer to q9 – client setting, branches to living at Home or living in Facility section}

1. IF HOME BASED, CONTINUE W/ Q82, ELSE:
2. ASSISTED LIVING: GO TO FACILITY BASED SECTION (skip to Q 100)
3. ADULT FOSTER CARE: GO TO FACILITY BASED SECTION (skip to Q 100)
4. NURSING HOME: GO TO FACILITY BASED SECTION (skip to Q 100)

****

BEGINNING OF CAREGIVER/SERVICE QUESTIONS—LIVING AT HOME (Q82-Q99)

Question 82

The next questions ask about the services {you receive|name receives} at home.

We are interested in knowing how satisfied you are with the in-home services provided to {you|name}.

I am going to read a list of services available to {you|name} in a home setting. Please tell me which is the most important service {you receive|he receives|she receives}.

1. Attendant Care
2. Housekeeping
3. Personal Care Aide
4. Home Delivered Meals
5. Nursing Care
6. Home Health Aide

7. PROXY IS CAREGIVER (SKIP CAREGIVER QUESTIONS) (skip to Q 130)
8. DOESN'T GET ANY SERVICES AT HOME (skip to Q 130)
9. DK/REF (skip to Q 130)

****

Question 83

Is this the same {caregiver} {you|name} had the last time we spoke with you?

[SINCE LAST OCTOBER]

[INTERVIEWER: IF ‘R’ WAS NOT IN THE PREVIOUS STUDY, ENTER ‘9’]

1. YES
2. NO

9. DK/REF

****

Question 85

The next few questions are about the services {you receive|name receives} from the {caregiver}.

Overall, how satisfied are you with how the {caregiver} listens to you?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 86

Overall, how satisfied are you that {your|name's} {caregiver} involves you when making decisions about {your|name's} care?

Would you say you are: very satisfied, satisfied, dissatisfied, very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED
5. DOESN'T APPLY TO RESPONDENT

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 87

How easy is it for you to reach {your|name's} {caregiver}?

Would you say it is very easy, easy, hard, or very hard?

1. VERY EASY
2. EASY
3. HARD
4. VERY HARD

5. DOESN'T APPLY TO RESPONDENT (skip to Q 91)

8. NEUTRAL/NEITHER
9. DK/REF

****

Question 88

When you call {your|name's} {caregiver}, how satisfied are you that {you get|name gets} the help {you need|he needs|she needs}? Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED
5. DOESN'T APPLY TO RESPONDENT

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 91

How satisfied are you with the respect shown by {your|name's} {caregiver} for what you have to say?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 95

How satisfied are you that {your|name's} {caregiver} takes into consideration {your|his|her} special cultural needs? Would you say you are: very satisfied, satisfied, dissatisfied, very dissatisfied or does this not apply to you?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED
5. DOES NOT APPLY

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 96

Overall, how satisfied are you with {your|name's} {caregiver} now?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED (skip to Q 98)
4. VERY DISSATISFIED (skip to Q 98)

8. NEITHER/NEUTRAL (skip to Q 130)
9. DK/REF (skip to Q 130)

****

Question 97

What is the main reason you are satisfied with {your|name's} {caregiver}?

Is it because he or she listens to you, involves you in planning services, treats you with respect, is your advocate when necessary, is accessible, helps you retain your independence, considers race, beliefs and custom, or the quality of services received is good.

1. LISTENS (skip to Q 130)
2. INVOLVES IN PLANNING (skip to Q 130)
3. RESPECTS YOU (skip to Q 130)
4. ADVOCATE (skip to Q 130)
5. ACCESSIBLE (skip to Q 130)
6. RETAIN INDEPENDENCE (skip to Q 130)
7. CONSIDERS CULTURE (skip to Q 130)
8. GOOD SERVICES (skip to Q 130)

9. DK/REF (skip to Q 130)

****

Question 98

What is the main reason you are dissatisfied with {your|name's} {caregiver}?

Is it because he or she doesn't listen to you, doesn't involve you in planning services, does not treat you with respect, is not your advocate when necessary, is not accessible, does not help you retain your independence, doesn't consider race, beliefs and custom, the quality of services received is not good.

1. DOES NOT LISTEN (skip to Q 130)
2. DOES NOT INVOLVE IN PLANNING (skip to Q 130)
3. DOES NOT RESPECT YOU (skip to Q 130)
4. DOES NOT ADVOCATE (skip to Q 130)
5. ISN'T ACCESSIBLE (skip to Q 130)
6. DOES NOT RETAIN INDEPENDENCE (skip to Q 130)
7. DOES NOT CONSIDER CULTURE (skip to Q 130)
8. BAD SERVICES (skip to Q 130)

9. DK/REF (skip to Q 130)

BEGINNING OF CAREGIVER/SERVICE QUESTIONS—LIVING IN FACILITY (from Q9) (Q100-Q128)

Question 100

The next few questions ask you about the services provided by {Assisted Living|Adult Foster Care|Nursing Home} (From answer to Q 9).

I am going to read a list of services available to {you|name}. Please tell me which is the most important service {you receive|he receives|she receives}.

1. Nursing Services
2. Therapeutic Services
3. Social Services

9. DK/REF (skip to Q 130)

****

Question 101

Is this the same {caregiver} {you|name} had the last time we spoke with you?

[SINCE LAST OCTOBER]

[INTERVIEWER: IF 'R' WAS NOT IN PREVIOUS STUDY, ENTER '9']

1. YES
2. NO

9. DK/REF

****

Question 102

Overall, how satisfied are you that the {caregiver} listens to you? Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 103

Overall, how satisfied are you that {your|name's} {caregiver} involves you when making decisions about {your|name's} care?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED
5. DOESN'T APPLY TO RESPONDENT

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 104

How easy is it to reach the {caregiver} when you need him or her?

Would you say it is very easy, easy, hard, or very hard?

1. VERY EASY
2. EASY
3. HARD
4. VERY HARD
5. DOESN'T APPLY TO RESPONDENT (skip to Q 111)

8. NEUTRAL/NEITHER
9. DK/REF

****

Question 105

How satisfied are you that when you contact the {caregiver}, you get the help you need?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED
5. DOESN'T APPLY TO RESPONDENT

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 111

How satisfied are you with the respect shown by the {caregiver} for what you have to say?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED

8. NEITHER/NEUTRAL
9. DK/REF

****

Question 116

How satisfied are you that {your |name's} {caregiver} takes into consideration {your|his|her} special cultural needs? Would you say you are: very satisfied, satisfied, dissatisfied, very dissatisfied or does this not apply to you?

[Cultural needs refer to beliefs you were raised with, your family heritage, your religion, the foods you enjoy, and your lifestyle.]

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED
4. VERY DISSATISFIED
5. DOES NOT APPLY

8. NEITHER/NEUTRAL
10. DK/REF

****

Question 120

Overall, how satisfied are you with the {caregiver} now?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

1. VERY SATISFIED
2. SATISFIED
3. DISSATISFIED (skip to Q 126)
4. VERY DISSATISFIED (skip to Q 126)

8. NEITHER/NEUTRAL (skip to Q 130)
9. DK/REF (skip to Q 130)

****

Question 125

What is the main reason you are satisfied with the {caregiver}?

Is it because he or she listens to you, involves you in planning services, treats you with respect, is your advocate when necessary, is accessible, helps you retain your independence, considers race, beliefs and custom, or the quality of services received is good.

1. LISTENS (skip to Q 130)
2. INVOLVES IN PLANNING (skip to Q 130)
3. RESPECTS YOU (skip to Q 130)
4. ADVOCATE (skip to Q 130)
5. ACCESSIBLE (skip to Q 130)
6. RETAIN INDEPENDENCE (skip to Q 130)

7. CONSIDERS CULTURE (skip to Q 130)
8. GOOD SERVICES (skip to Q 130)
9. DK/REF (skip to Q 130)

****

Question 126

What is the main reason you are dissatisfied with the {caregiver}?

Is it because he or she doesn't listen to you, doesn't involve you in planning services, does not treat you with respect, is not your advocate when necessary, is not accessible, does not help you retain your independence, doesn't consider race, beliefs and custom, or the quality of services received is not good?

1. DOES NOT LISTEN
2. DOES NOT INVOLVE IN PLANNING
3. DOES NOT RESPECT YOU
4. DOES NOT ADVOCATE
5. ISN'T ACCESSIBLE
6. DOES NOT RETAIN INDEPENDENCE

7. DOES NOT CONSIDER CULTURE
8. BAD SERVICES
9. DK/REF

****

Question 130

Now we would like to ask you some questions about any problems you might have had with the services you get.

Do you know how to make a complaint about care or services {you receive|name receives}?

1. YES
2. NO (skip to Q 160)

9. DK/REF (skip to Q 160)

****

Question 131

Have you ever made a complaint?

1. YES
2. NO (skip to Q 160)

9. Dk/REF (skip to Q 160)

****

Question 131a

To whom did you complain?

[Where did you make your complaint]

[RECORD VERBATIM]

****

Question 132

Please tell me how satisfied you are with how fairly your complaint or concern was handled?

Would you say you are: very satisfied, satisfied, dissatisfied, or very dissatisfied?

[IWVR: IF MORE THAN ONE IN LAST 12 MONTHS, MOST RECENT COMPLAINT]

1. VERY SATISFIED (skip to Q 160)
2. SATISFIED (skip to Q 160)
3. DISSATISFIED (skip to Q 160)
4. VERY DISSATISFIED (skip to Q 160)
5. COMPLAINT HAS NOT BEEN SETTLED

8. NEITHER/NEUTRAL (skip to Q 160)
9. DK/REF (skip to Q 160)

****

Question 133

If your complaint has not been settled, have you been informed about how to get help from AHCCCS?

[IWVR: IF NECESSARY READ: If you have a complaint and shared it with Maricopa Long Term Care System, Lifemark, Mercy Care and it did not get resolved, do you know who to contact next?]

1. YES
2. NO

9. DK/REF

****

Question 160

How do you think AHCCCS could improve the long-term care program?

[CLARIFICATION for AHCCCS: the State; State government]

Verbatim answer recorded

****

Question 180

Just a few more questions.

Because persons who live alone may have different experiences with long term care than persons who live with someone else in their home, we'd like to ask about {your|name's} situation.

{Do you|Does name} live alone, {IF PROXY:} do you live with {name}, or does someone else live with {you|him|her}?

1. LIVE ALONE
2. SOMEONE ELSE LIVES WITH THEM (skip to Q 200)
3. PROXY LIVES WITH THEM (skip to Q 200)

9. DK/REF (skip to Q 200)

****

Question 181

And (do you|does name} have family members or a close friend nearby to assist {you|him|her}?

1. YES (HAS FAMILY/FRIEND CLOSE)
2. NO (ALONE)

9. DK/REF

****

Question 200

{Hidden question: Program checks to see if we are interviewing proxy or client. If proxy, Q201 is asked to help in the analysis of responses, otherwise we skip to Q 212}

****

Question 200a

Now we would like to a few questions about you. Remember all information is confidential.

What is your relationship to {name}?

1. SPOUSE (skip to Q 201)
2. PARENT (skip to Q 201)
3. SIBLING (skip to Q 201)
4. SON/DAUGHTER (skip to Q 201)
5. LIVE IN COMPANION (skip to Q 201)
6. AUNT/UNCLE (skip to Q 201)
7. GRAND SON/DAUGHTER (skip to Q 201)
8. COUSIN (skip to Q 201)
9. FIDUCIARY (skip to Q 201)
10. FRIEND (NOT LIVING WITH) (skip to Q 201)
11. PARENT IN LAW (skip to Q 201)
12. SON/DAUGHTER IN LAW (skip to Q 201)

88. OTHER (SPECIFY AT NEXT QUESTION)
99. DK/REF

****

Question 200b {Only asked of '88' responses to Q200a}

What would that be?

Verbatim answer recorded

****

Question 201

We'd like to know how involved with {name's} care you are.

Would you say you are you involved with {his|her} care on a daily basis, a few times a week, a few times a month, or less often?

[INTW: "INVOLVED WITH CARE" IS EVERYTHING: ACTUAL CARE, DR VISITS, TALKING TO CASE MANAGER/DOCTOR/CAREGIVER]

1. DAILY
2. FEW TIMES A WEEK
3. FEW TIMES A MONTH
4. LESS OFTEN

9. DK/REF

****

Question 201a

Do you help with {name}'s legal needs such as serving as an executor of a will?

1. YES
2. NO

9. DK/REF

****

Question 201b

What about providing regular medical care such as giving medicine, taking blood pressure or checking blood sugar levels?

1. YES
2. NO

9. DK/REF

****

Question 201c

What about helping with daily living activities such as assisting with housekeeping, cooking, laundry, bathing, or personal hygiene?

1. YES
2. NO

9. DK/REF

****

Question 201d

What about providing assistance with financial matters, such as paying bills or depositing checks?

1. YES
2. NO

9. DK/REF

****

****

Question 210
{Hidden question: checks Q 180. Goes to Q 212, if client lives at home, or to Q250}

****

Question 212

Do you live in Maricopa County, somewhere else in Arizona, or out-of-state?

1. NEARBY, MARICOPA COUNTY
2. SOMEWHERE ELSE IN ARIZONA
3. OUT-OF-STATE

****

QUESTION 250

Finally, what is your age?

REFUSAL = 99

[Interviewer enters respondent's age, or '99' for refusal]]

****

QUESTION 300

And that concludes our survey. Thank you very much for your cooperation.

FOR QUESTIONS ABOUT SERVICES: you can call your case manager or your health care provider:
Maricopa Long Term Care System -> 602-344-8700.
Mercy Care -> 1-800-624-3879 OR 602-555-1212
Lifemark -> 1-800-293-3740

FOR QUESTIONS ABOUT OUR QUESTIONS: If you have questions about this study please call Marilea Rose at Health Services Advisory Group, 602-665-6138.

****

Question 400 {Interviewer completes these after hanging up}

Rate the respondent's understanding of the questions.

1. R understood all or almost all the questions
2. R had difficulty understanding a couple of questions
3. R had difficulty understanding more than 10 questions
4. R had difficulty with a lot of questions

****

Question 401a

Was language a problem?

1. YES
2. NO

****

Question 401b

Was hearing a problem?

1. YES
2. NO

****

Question 401c

Is there anything else we need to know about any difficulties the respondent had?

1. YES (ENTER AT $ PROMPT) (skip to q 998c)
2. NO (skip to q 998c)

****

{These are help/reference screens that are available to the interviewer from any screen where needed. They are only used when required; interviewers read sections from them as needed.}

Question 995k
BEGINNING OF BOUNCE-BACK QUESTION(S) FOR HELP OR REFERENCE
[SURVEY PURPOSE AND CONFIDENTIALITY]

We are doing this survey to find out about people's opinions of their long term care.

We want to find out your experiences with the care you receive.

We are NOT selling anything - we work for Arizona State University.

You may call my supervisor and ask him any questions, or verify this survey: JoAnne Valdenegro or Bill Edwards, 480-965-5009.

If you want to verify with AHCCCS, please call John Black at 602-417-4055.

You may also call HSAG if you have questions, call Marilea Rose at 602-665-6138. (Health Services Advisory Group)

I had to sign a statement promising to keep secret all the answers I heard, and so did all the other interviewers and my supervisors.